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COUNSELLING IN INFERTILITY: SCOPE AND LIMITATIONS – A PROFILE OF COUNSELLING SERVICES IN AUSTRALIAN ASSISTED REPRODUCTIVE CLINICS

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ABSTRACT

Not having children in what still remains a pro-natalist society causes significant loss and grief. Approximately one in six couples today experience difficulty in conceiving. In response to the increase in the number of people seeking treatment there has been a spectacular increase in the number of fertility clinics established throughout Australia. Clinics are required to provide patients with counselling; however, little is known about counselling in this context. This paper charts the development of Assisted Reproductive Clinics in Australia and the requirement for counselling to be provided. It reports on results from an exploratory study, carried out in 2000, examining the role and extent of the counselling services that are provided in Australian fertility clinics. Forty eight clinics were sent a questionnaire with a 60% response rate.

The results indicate that counselling is provided for a wide range of issues that people experience during fertility treatment. The provision of support and information was ranked most highly. What is most striking are the relatively low numbers of people who take up the offer of counselling. The authors discuss why this might be the case and calls for further exploration of peoples' experiences.

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INTRODUCTION

The essentialness of having children is a recurring issue of public debate. Over the past year there has been significant discussion of Australia's declining fertility rate

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and what this might mean for future generations. Stories about why women are choosing not to have more children or why they are not having children are regularly presented in the popular press. The Prime Minister, John Howard, recently argued against same sex marriages on the basis that "Marriage, as we understand it in our society, is about children, having children, raising them, providing for the survival of the species..." (www\\ABC online, Door stop interview, Darwin, 5th August 2003). What these public discussions reflect is how the ideal of having children is maintained and constructed as a central role for people, particularly women in our society. It would seem that no matter how strongly the dominant discourse of parenting is questioned, with individuals and couples making choices about parenting, it remains an extremely powerful set of messages. Therefore when couples can not fulfil society's and their own expectations of having 'a family' it may be seen as a major life crisis involving a rethinking of the couple's life and identity (Bergart 2000; Brown 1998; Aneu 1993; Daniels 1993).

In Australia about 15% of couples of reproductive age experience fertility issues (Ford, Nassar, Sullivan, Chambers, and Lancaster 2002). Social changes particularly the changing role of women has meant that more women are delaying pregnancy and experiencing a subsequent impact on their fertility. These women are more likely to seek advice and treatment (Dean and Sullivan 2003, National Bioethics Consultative Committee 1991).

In response to the increase in the number of people seeking treatment there has been a significant increase in the number of clinics established throughout Australia that provide treatment for infertility. According to the Australian Institute of Health and Welfare, the number of Assisted Reproductive Technology units has grown from 21 in 1993 to 34 in 2001 (Dean and Sullivan 2003).

These clinics provide assisted reproduction services to couples, and in some States in Australia individuals, with an ever-increasing expansion of types of intervention. To be accredited these services must provide counselling for people accessing assisted reproductive treatment. Underpinning the existence of these clinics is the assumption that for most people the experience of infertility or being involved in fertility treatment is a time where counselling is thought to assist with the difficult emotional and psycho social processes related to childlessness and treatment (National Bioethics Consultative Committee 1991).

Much has been written about the horrors, hardship and risks of the IVF treatment (Brown 1998; Klein 1989; Alden 1996). There are large emotional and economic costs involved which put enormous strain on couples and individuals. Long-term treatment can mean interrupted careers, a slavish commitment to treatment, and an inevitable sense of isolation. The dominant discourse of the essentialness of having

children also places pressure on individuals and couples to keep trying to have a child. Although portrayed in the popular press as a miracle cure, infertility treatment is certainly not a 'quick fix.' There are great physical and emotional stresses and strains on both the individuals involved and their relationships.

The purpose of our exploratory study, carried out in 2000, was to develop a profile of the role and extent of the support services that are provided in Australian fertility clinics. Although there are clear guidelines about the need for such services in Australia, few data exist about who provides counselling services, what is being done in the name of counselling and what role it plays in assisting couples in the decision making never mind the somewhat inconclusive evidence that counselling is effective in reproductive medicine (Eugster and Vingerhoets 1999).

A brief overview of the impact of infertility and treatment and hence the need for counselling follows. This section outlines the development of the requirement to provide counselling in clinics in Australia.

EFFECTS OF INFERTILITY AND TREATMENT

There is consensus in the large body of literature available on this subject that the psychological effects of infertility can be very profound. Although its effects on individuals are unique, it has often been described as an 'emotional life crisis' involving very strong feelings . These include intense grief (Alden 1996, 8) which is "difficult to deal with because it is unfocused and intangible" (Jennings 1995, 233; strong anger (often turned against oneself); guilt; frustration; and despair (Anton 1992; Leiblum 1997; Winston 1986; Zoldbrod 1993). Other 'difficult feelings' such as hopelessness, obsession, envy, jealousy and hostility are also frequently reported (Anton 1992; Leiblum 1997). According to Leiblum (1997, 58) "it can be as disabling as many diseases and can lead to chronic unhappiness, depression and the destruction of relationships".

Furthermore, the issue of infertility is often a taboo subject, shrouded in secrecy, with an enormous stigma attached to it (Klein 1989; Miall 1986). Those individuals affected by infertility often describe feeling 'out of control', 'defective' and 'inadequate' (Leiblum 1997). Brown (1998, 107), for instance, explains that in addition to natural defence mechanisms like avoiding situations with children and pregnant women, couples also withdraw socially, fearing adverse judgment by their peers. They do not want to risk the appearance of being ' too stressed and depressed to conceive' or of being associated with the stereotype of 'selfish, sorrowful childless couples'. As a result, they suffer deeply from a severe sense of isolation and nonbelonging. Infertility can have long-lasting effects on marital, sexual, social and familial relationships.

For those who choose to seek medical treatment there are also a number of issues related to the choice of medical treatment, the impact of the processes and medical procedures (which can increase levels of stress emotional strain and anxiety) the likely side-effects of the drugs administered, a perceived loss of control and the feeling of 'putting their life on hold' (Zoldbrod 1993; .

It is a strongly held view that as people experience a range of complex issues surrounding infertility treatment counselling is beneficial and can help (Strauss and Boivin 2002; National Bioethics Consultative Committee 1991; Bergart 2000).

Counselling – defined by Daniels (cited in Strauss and Boivin 2002) is 'an interpersonal process, based on a theoretical framework, which (was) used to bring about change in a skilled and systematic way''. It is according to Strauss and Boivin (2002) about support and the clarification of life goals'. It can be provided in a variety of forms and at different stages of people's journey through infertility treatment.

THE DEVELOPMENT OF ASSISTED REPRODUCTIVE TECHNOLOGY (ART) CLINICS IN AUSTRALIA

Since Australia's first IVF birth in 1980 the number of public and private fertility centres has grown so that in 2000 there were 34 assisted reproductive clinics operating throughout metropolitan, regional and country areas of Australia offering a comprehensive range of services (Dean and Sullivan, 2003). As a measure of the extent of assisted reproduction in Australia, the number of treatment cycles for all types of assisted conceptions increased from 16,288 in 1992 to 27,067 in 2000 (Dean and Sullivan 2003).

The development of counselling in ART programs.

Since 1982, the regulation of assisted reproductive technologies has become complex. In addition to guidelines, in three Australian States: Victoria (1984) South Australia (1988) and Western Australia $(1991)^1$ clinics are regulated by specific legislation. There is a system of self-regulation and accreditation carried out by the Reproductive Technology Accreditation Committee (RTAC²). It has a code of practice for units using IVF and related reproductive technologies. RTAC also sets professional and laboratory standards for clinical practice under this system of accreditation.

¹ Queensland has unique legislation (1992) prohibiting surrogacy but otherwise, IVF works under a set of guidelines established in 1984. There is no specific legislation in the other states (Australian and New Zealand Infertility Counsellors Association Website).

² RTAC is self-funded by IFV clinics, a voluntary process that has been accepted throughout Australia (Australian and New Zealand Infertility Counsellors Association)

National health policy in Australia has recognised the importance of counselling for couples who access reproductive programs. The Australian National Bioethics Consultation Committee (NBCC) established in 1988 examined the issues related to infertility counselling. In its recommendations the NBCC looked at ways to extend the counselling services provided in the context of health care services to the area of infertility 'where it had been neglected'. It identified the role and nature of counselling required and also suggested directions regarding preferred service delivery frameworks such as when counselling should be provided.

The NBCC recommended that 'competent' counselling be routinely provided by clinics in order to 'provide emotional support, information, decision making and therapeutic counselling to consumers and that these services be provided as part of a general cycle treatment cost'. The committee's report also suggested routine provision of counselling in all infertility programs at each stage including before treatment, after admission, after treatment and when a decision is taken to discontinue treatment.

There have also been a number of state government enquiries and reviews examining counselling in .ART programs. For example Western Australia, where legislation and regulation had already been introduced covering the provision of mandatory counselling services in ART programs (including a system of professional accreditation), enacted regulations incorporating a specific model of service delivery. This includes access to an approved counsellor for one hour for each IVF cycle, as well as one extra hour when the decision is made to withdraw from further treatment (Reproductive Technology Council 2001).

There may be no legislative requirement in some states to provide counselling in clinics but there is a financial incentive. The accreditation process for clinics is relevant to whether the Health Insurance Commission approves fertility drugs used by the clinic. Therefore compliance with NHMRC guidelines is required to provide counselling of a support or therapeutic nature as an 'integral part of any ART program' (Willmott and Kift 2000, 22).

Today most ART programs have a salaried counsellor on staff or at least retain the full or part-time professional services of one.

Timing and types of counselling

The NBCC's consultations with consumers on the role of infertility counselling identified three major points of decision-making which were critical for counselling: the initial stage prior to entry into a program; the medical treatment to reproductive technology stage and the medical treatment to alternatives stage. This third stage is crucial given the high percentage of consumers where a baby is not the end result

(National Bioethics Consultative Committee, 1991; Jansen 2003). The loss of control experienced within the medical process is difficult to regain and the need for support and therapy to implement or maintain the decision to withdraw from the program is of paramount importance.

The Australian and New Zealand Infertility Counsellors Association, who have developed the guidelines for clinic accreditation, state that

Counsellors offer services, which include psychological counselling, information, crisis counselling and follow up support. This may include psychotherapy for ongoing problems or arrange a referral to another service for continuing management (The Fertility Society, Reproductive Technology Accreditation Committee Code of Practice 2002, 18).

Counsellors in the field may have to reconcile the various demands of infertility counselling, that is, screening and assessment and information provision on the one hand, and facilitating decision making and providing therapeutic counselling on the other. Some questions over the effectiveness and quality of counselling provided, particularly in relation to decisions to discontinue treatment remain. In Britain in 2000 the Royal College of Obstetricians and Gynaecologists carried out an extensive review into the role and effectiveness of counseling. The report argued that 'more research is needed to explore the appropriateness of specific interventions for particular populations at different stages of the various fertility treatments, including when treatment has ended' (2000, 11).

There are also little data available that indicate who is provides counselling services (ie what health or welfare professionals) or what the primary focus is or should be of counselling (for example assessment or therapeutic counselling). The professional qualifications of the counsellor may have a very significant impact on service provision and the focus of the counselling . For example social workers because of their training are able to take a broader approach to their client's issues than other types of health professionals (Daniels 1993; Blyth 1999).

There is also little information about whether clinic clients take up the offer of counselling. The only information we identified was an audit of counselling carried out by the Western Australian Reproductive Council who found that 75% of clients who received counselling had only one session (Western Australian Reproductive Technology Council 2001). This audit also found that counsellors were only available in the clinics on a sessional basis often for only two or three sessions per week.

The research project described here provides a profile of counselling services in assisted reproduction clinics in Australia in an attempt to have a clearer picture of the delivery of counselling services.

THE RESEARCH PROJECT

Method

In April 2000 a national mail out survey of the 48 assisted reproduction clinics in Australia was carried out. Although at the time there were only 34 accredited clinics there are a number of satellite clinics in regional areas which were included in the survey.

The questionnaire was addressed to the clinic counsellor. The questionnaire requested information about:

- the provision of support services,
- who provides the counselling, the extent of counselling,
- the role and use of counsellors,
- the role in assisting couples to cease treatment.
- The level of take up of counselling

Results

State/Territory	Number of Clinics
ACT	1
Victoria(urban)	6
Victoria (rural)	1
NSW (urban)	4
NSW (rural)	2
Queensland (urban)	4
Queensland (rural)	2
Northern Territory	1
South Australia	3
Western Australia	5
Total	29

Surveys were returned from clinics throughout Australia except for Tasmania. The participating clinics were based in both urban and rural settings. This is a good response rate of sixty percent and goes some way to develop a picture of counselling services provided at clinics across Australia.

The Nature of Reproductive Services

Clinics who responded to the survey each treated over 100 people annually and provided a wide range of services including tracking, artificial insemination and IVF. All clinics in the sample provided IVF and donor gamete services with four clinics providing surrogacy services.

The Counselling Services

Clinic counsellors were asked to indicate whether counselling was provided at the clinic. Not surprisingly due to the legislation and accreditation requirements all respondents indicated that patients received 'counselling' with treatment. In most cases (17/29) in-house staff provided the counselling. However it would appear that in over half of the clinics external counsellors provided counselling as well. Most clinics employ part time counselling staff with only two clinics stating they employed full time staff.

Respondents were asked to rank the main purpose of the counselling provided at the clinic. Some respondents indicated that a full range of issues was equally important. However the majority of respondents (19/29) ranked the provision of information and ongoing support most highly. Assistance with decision making was ranked mainly 2^{nd} or 3^{rd} by about half of the respondents. 26 out of 29 respondents ranked follow up of clients as a lower ranked issue.

Respondents were asked whether they had a particular area of counselling specialisation. Over two thirds indicated that they focused on the full range of issues with their clients including family and relationship counselling, grief counselling and stress management.

Half the clinics that responded have the services of either a social worker or a psychologist. Only 2 clinics employed both, 12 clinics employed only psychologists whereas 8 clinics employed only a social worker. There were 4 clinics that provided counselling through a 'qualified counsellor' and 5 clinics that provided counselling services by nursing or medical staff.

	Counselling provided by	Referred to
psychologists	12	13
social workers	8	2
qualified counsellors	4	3
nurses or medical staff	5	Na
specialised counsellor	1	6
eg genetic counsellor)		

Table 2: Qualifications of counsellors

Table 2 also indicates where clients were referred to for further counselling. Seventy six per cent (19) of clinics refer to psychologists and 10 clinics indicated they referred to specialised counsellors such as genetic counsellors. Social workers were referred to by 7 clinics. It is not possible to distinguish whether these professionals are employed in private practice or by the public sector eg a hospital or community health service or even organisations such as Relationships Australia. However the only other research examining this issue indicates very small numbers of counsellors in the community see people with fertility issues (Reproductive Technology Council 2001).

Counselling after an unsuccessful treatment is thought to provide an opportunity to impress upon clients the importance of taking adequate pauses in treatment, and to assess and consider the next step. Clients may speak to their doctor to discuss their options but it would appear that many people do not take up the offer of follow up counselling or are not made aware that it is available. We asked counsellors to estimate the proportion of clients who take up counselling after unsuccessful treatment.

From the table below we can see that 15 counsellors (55.5%) estimate less than 20% of clients take up follow up counselling. In 7 clinics respondents indicated between 20% and 50% of patients take up follow up counselling.

	Frequency	Percent
less than 20%	15	55.5
20-50%	7	26
50-80%	3	11.5
other/don't know	2	7
Total	27	100
Missing	2	
Total	29	

 Table 3: Percentage of clients who take up offered follow up counselling

Clinic respondents were asked to rank the top three reasons why patients took up the offer of follow up counselling. We have aggregated the reasons and the data is displayed in the table below. The most common reason for seeing a counsellor was (in the view of the counsellor) dealing with the emotions related to the infertility treatment. The second most common reason was help in coping with the experience of treatment. As can be seen from Table 4 only 6 respondents indicated that patients came to discuss the decision of what to do next after a 'failed attempt'.

Reason	Number of respondents
Emotions	23
Coping	18
Health	13
relationships	10
information	8
complications	7
decision making	6

Table 4: Reasons why patients come for follow up counselling

Respondents were asked why they thought clients did not take up counselling. There are a wide variety of reasons given but three major themes emerge. The first is the view that counselors believe clients don't feel they need follow up counseling. Some counselors indicate that this because they don't think patients know enough about counselling, what is it or even that it is available. One respondent even raised the issue of the cost of counselling as a barrier to taking up counselling.

The second group of reasons is the fear of stigma –a lack of trust of the clinic or possibly feeling vulnerable in the clinic environment. Below are some examples of what clinic counsellors say about this:

- they don't want to risk appearing like they are not coping
- the clinic staff are too painful to see
- (the) low self esteem associated with infertility means that they feel more inadequate if they ask for help, (there is) stigma associated with counselling
- (it is seen as an) admission of 'failure', difficult to ask for help, want to appear strong and coping to clinic staff,

End of Treatment Counselling

Finally we asked the clinic counsellor whether counselling was offered at end of treatment when and if they knew that the couple or individual had decided to withdraw from medical intervention. One of the issues raised in the literature is that following infertility treatment there is very little in the way of continuing counselling for couples who fail to achieve a live birth, and do not opt for adoption. There is a sense that they are no longer being part of a clinical program, they are out on their own and must fend for themselves which can be a lonely and difficult process (Johnston 1994; Winston 1986).

Fourteen clinics indicated that patients were routinely offered counselling at this point and seven clinics indicated this did not happen. About half of the clinics indicated that clients were offered counselling to assist in stopping treatment either always or often. We asked if counselling was offered why patients may not take up this offer. The main reasons respondents gave was the view that 'patients make their own decisions' (5/29); 'patients believe they can cope' (4/29) and 2 respondents who indicated that this type of counselling was not offered at their clinic.

All the respondents stated that they referred clients to other agencies that may be more appropriate in dealing with the issue of ceasing treatment. This result may reflect the awareness of what could be perceived as a conflict of interest. That is clinics provide treatment for fertility issues and may not be in the best position to provide assistance in deciding to stop. However this does leave us with the question of where they are referred.

Limitations of the survey

The survey was an opportunity to provide information about the counselling available in ART programs and the time frame within which people seek counselling while undergoing treatment in Australia. The questionnaire was able to be quickly completed it leading to a good response rate. However the depth of information it provides about counselling services is limited.

Although we did receive information from 60% of clinics we did not receive information from all clinics -so there is not a complete picture. It is unclear how different the clinics who didn't answer might be compared to those in the sample discussed above. Notwithstanding these limitations the survey has provided important information about counselling in Australian clinics.

DISCUSSION AND CONCLUSIONS

The purpose of this paper was to discuss the role of counselling in assisted reproductive technology programs and to carry out a small research project which surveyed all clinics in Australia. The aim was to develop a better understanding of the role and extent of the support services they are able to provide. Our literature review found limited data about who provides counselling services, what is being done in the name of counselling and what role it plays in assisting couples in the decision making around their treatment.

The respondents to the questionnaire state that they provide counselling about a wide range of issues that people experience during fertility treatment. Providing support and information ranked most highly. Most clinics employed counsellors in house but mainly on a part time basis and most were either social workers or psychologists. Only 5 clinics indicated that nurses or medical staff was involved in the counselling process. It would appear that most clinics commonly refer people to community or

specialized counsellors however where they are located cannot be identified by the questionnaire.

The majority of clinics estimate that less than 20% of people take up the offer of follow up counselling. Respondent suggested that the low take up rate was for three main groups of reasons: clients don't think they need counselling, they don't understand what counselling is or know that it is available and finally the stigma of being seen not to cope by clinic staff was a barrier.

These figures are supported by an audit carried out in 2001 by the Western Australian Reproductive Council which found that few people take up more than one session of counselling and were also not accessing counselling in the community again they view being they didn't need it. When patients were asked why they did not access counselling same reason emerges – they say they do not think they need counselling.

The literature indicates that people experience significant and long term emotional issues due to infertility and infertility treatment however the limited data we have indicates they do not see counselling as something they want or that can help. There may be a variety of reasons for this. A study by Boivin and her colleagues carried out in 1999 found that a principal barrier for such patients was the practical aspect of getting help. The study showed that if they were contacted personally more people accessed counselling.

Further reasons maybe the individual resilience and level of support people have. As increasing numbers of people don't have children possibly there is a weakening of the dominant parenting discourse providing other life choices for people and reducing their need for assistance. However longer term follow up is required to explore these reasons more fully.

On the other side maybe the timing of the counselling offered is problematic or the context in which it is offered is not appropriate or maybe there is a lack of understanding of what counselling can do or what it is. As one clinic respondent stated people may think counselling is for those who have 'problems'. As the issue of infertility is still regarded as taboo in our society it might be unlikely that individuals and couples will actively seek counselling although they may be experiencing ongoing grief and loss. There is also the question of whether individual counselling is the best choice of intervention. Perhaps self-help through a support group is a more effective and appropriate option. As with the role and effectiveness of counselling in this area there is little research available with which to make clear judgments.

This survey identifies some important questions about the support provided for people who experience infertility treatment and the role counselling plays in this process. More research is required to understand their experiences.

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