

# A group-work approach in family building by donor insemination: empowering the marginalized

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Family building with donor insemination (DI) is often perceived as stigmatizing and the secrecy surrounding the practice contributes to this perception. In recent years, patient organizations in several countries have started to challenge this stigma and marginalization. This paper reports on a professional group-work approach for couples in Germany using DI. Participants of four seminars with a total of 74 participants and a return rate of 89% were asked to report on their expectations of and experiences during the seminars. Participants were asked to comment on their views and perspectives regarding DI practice. The results indicate a need for more information on DI and for the opportunity to meet other couples in the same situation. Participants also argued for normalization and social acceptance for families built by DI. The group-work approach described in this paper contributes significantly towards fulfilling the needs of couples involved in DI.

Parents who have used donor insemination (DI) to enable them to build their family often report feeling stigmatized by the experience of infertility (Miall, 1989) and using DI (Whiteford and Gonzalez, 1995; Nachtigall *et al.*, 1997). The secrecy that has traditionally surrounded DI has been a major factor in this stigmatization (Daniels and Taylor, 1993). If couples or individuals are advised by their doctor or health professional not to tell anyone, including their offspring, about the nature of the conception, then they are being implicitly told that what they are doing is shameful.

It is to be expected that families will want to restrict the number of people who know about 'shameful' events, and secret keeping is the established way to do this. Therefore, the provision of group work for people with secrets may be seen as a contradiction, in that participants reveal their 'secret' when they join a group.

In Germany, DI has been practised for at least 50 years (Krause, 1985). In the 1950s, it was considered morally dubious and treatment with DI was deemed to go against the medical code of practice. However, DI was still carried out, but in secret. In addition, both the Roman Catholic and the Protestant Churches have issued statements against the practice of DI (Evangelische Kirche, 1987; Lexikon der Bioethik, 1998). Although DI has become less objectionable in recent years, open acknowledgement and discussion of it is not usual, and for many it remains a questionable practice.

A relatively recent phenomenon in the field of DI has been the development of consumer organizations that embrace

parents, offspring and donors. Such organizations now operate in countries such as the UK, Sweden, Germany, the USA, Canada, Australia and New Zealand. These organizations are contributing to challenging the notion that DI is, in some way, shameful and they are questioning the notion of stigma that has historically been associated with it. Most of these organizations argue strongly against the established practice of secrecy. Those who join such organizations often describe feeling liberated and supported as a result of being able to talk with others whose families were also built with the assistance of DI. Consumer organization newsletters contain many personal accounts that reflect this feeling.

There are few reports published of group work in DI. This is in contrast to the more extensive literature on group work in infertility beginning with the study of Wilchins and Park (1974). The slow evolution of the use of groups in DI programmes is almost certainly the result of the pervading culture of secrecy.

This article reports on a 'group-work' approach to DI family building in Germany. Since 1996, eight seminars have been conducted for those who plan to use DI, are in treatment or have children as a result of DI. As oocyte donation and surrogacy are both legally prohibited, these forms of third party reproduction are not included in the seminars and this evaluation. However, the psychosocial issues associated with these procedures are likely to be similar and we believe that the content of the seminars and the results presented in this paper are relevant too to those forms of third party reproduction.

The seminars were held over a weekend and were organized and facilitated by the first author. Seminars involved other professionals, a doctor who discussed the medical aspects of DI and a lawyer who outlined the legal implications of DI parentage. Three of the seminars were co-facilitated with the second author whose role in the seminars was to present an overview of international developments concerning psychosocial factors of DI-family building and to assist in the group discussions. There was some group discussion on the first day, and the second day was entirely group discussion. For part of the second day, men and women were divided into separate groups. In addition, a couple who had two children as a result of DI and who had talked with their children about their conception shared their experiences.

At the time that the seminars began, the reaction of many doctors towards infertility counselling in general and especially about the formation of information and preparation seminars for DI was reserved, and these conservative attitudes about the treatment were reflected in the lack of recommendations to couples to seek counselling or attend such seminars. The initial low attendance at the seminars reflects the attitude prevalent

in many countries where DI is a taboo subject (Baetens *et al.*, 2000). The lack of media awareness and interest, along with the limited literature available on this form of family building in Germany (Hanschel, 2000) are also likely to have been contributory factors.

The seminars were primarily educational in design, providing an opportunity for couples not only to receive comprehensive information on the medical, legal and psychosocial issues related to DI but also to help them to get to know other couples in the same situation. It was expected that the support and information participants received from each other and the professionals involved would empower them to see and use this method of family building in a healthy and creative way. A major component of the programme was overcoming feelings associated with the perceived stigma and shame in a way that did not leave participants feeling marginalized.

After a discussion of marginalization and stigma in DI, this paper will report on and discuss the evaluations of the participants of their experiences in the seminars. These evaluations indicate that the seminars were successful in empowering participants.

### **Marginalizing experiences: infertility and the use of donor insemination**

Being different from the majority of a family, group, community or society means that one is 'noticed' because of the difference. Some differences can be observed, such as being of a different ethnicity to the majority of the community or living with a physical disability in an able society, but other differences, such as infertility, may not be so obvious. Some differences may be highly valued, whereas others may be seen in a negative way. Therefore, for the individual who is different, two factors contribute to their perception of the significance of that difference. First, how the difference is perceived and, second, how that person interprets others viewing the difference. Goffman (1963) uses the term 'stigma' to describe the negative characterization that may occur when the difference is not viewed as being of value. The social identity of a person is clearly influenced by such stigma.

The notion of stigma has been widely used in relation to infertility (Miall, 1986, 1989; Schaffer and Diamond, 1993; Nachtigall *et al.*, 1997). Veevers (1973) stated that it is the expectation or norm that all married couples will reproduce and further that they will want to reproduce (Veevers, 1973). Therefore, not being able to fulfil a strongly held and accepted social norm is likely to lead to self-perceived inadequacy and can thereby be associated with feelings of defect and stigma (Schaffer and Diamond, 1993). These perceived inadequacies could lead to what Goffman (1963) describes as the development of a 'spoiled identity'.

The idea of difference was developed by Kirk (1964) in his studies of adoption after infertility in which he suggested that people respond to adoption by acknowledging or denying the lack of biological connections. Kirk (1964) concluded that those who acknowledged difference tended to be more open about adoption, and those who rejected difference were more likely to be secretive. The present study indicates that a similar pattern occurs in relation to those who use DI. The rejection of difference (when a semen donor was used), perhaps because of the fear of stigma, leads to the keeping of secrets. These secrets

have the potential to marginalize those who use them and who always have to pretend to be something they are not in order to conform to actual or perceived societal norms and expectations. Furthermore, the dominant discourse, which has maintained the subjugation of DI under a veil of secrecy, has reinforced the views of many parents regarding their use of DI. The sense of shame and potential stigma is described by Schaffer and Diamond (1993) as 'the protective response of secrecy, which, in turn, works to maintain and prolong the sense of shame'. In this analysis, the marginalized remain marginalized because the stigma is not questioned or challenged, thus perpetuating the self-fulfilling prophecy of shame.

Doctors and other health professionals working in infertility and assisted reproduction have traditionally sought to protect couples and individuals by encouraging secrecy (Leader *et al.*, 1984). Although such intentions may have been well meaning, there have been implications that were not foreseen:

- tension is created when there are family secrets (Baran and Pannor, 1993)
- decision-making on these issues is influenced by professional paternalism which has the potential to further disempower and marginalize individuals (Bailey, 1999)
- the symptom rather than the cause is dealt with; that is, the stigma of infertility and assisted reproductive technology as the casual factors are not challenged (Broderick and Walker, 1999)
- an increasing number of offspring who know they were conceived as a result of DI are objecting to the decisions that were made nominally on their behalf and the lack of consideration that was given to their needs and interests at the time the decisions were made (Cordray, 1999; Turner and Coyle, 2000)
- secrecy implies that an important part of the history of a family is not acknowledged, which may imply that this is associated with shame, making it difficult for parents to share with their children the way their family was built (Daniels and Thorn, 2001)
- an increasing number of semen donors do not wish to perpetuate the stigma and secrecy and are willing to be available for meetings with offspring, should this be requested (Daniels, 1998)

It is against the backdrop of such changes, all of which are of relatively recent origin, that the groups reported on here began. The people attending such groups, in different ways and for different reasons, wish to question their marginalized status. Providing opportunities for participants to meet others in similar circumstances, gain support and increase their understanding of DI family building are seen as a means of empowering them and thus work towards the normalization of their use of DI. The authors are grateful to those who attended the seminars for allowing them to use their experiences to contribute to the rich data gathered for this paper.

### **Methodology**

#### *Methods of data collection*

Information was collected from 66 of the 74 participants in four seminars held between October 1999 and February 2001

**Table 1.** Socio-demographic information about participants in a 'group-work' approach to donor-insemination (DI) family building in Germany

	Number	%
Responses	66 of 74	89
Marital status		
Single	1	1.5
Married	60	91
Living together	4	6
Divorced	1	1.5
Age		
Unknown	1	1.5
25–29	9	14
30–34	30	45
35–39	19	29
40 plus	7	11
Occupation		
Unknown	1	2
Trades, sales and administration	33	50
Professional	32	48
Children		
None	62	94
DI	4	6

in Germany (89% response rate). The participants of four earlier seminars were not included as a different type of evaluation was used. At the end of the seminar, participants were asked to complete a questionnaire anonymously. The questionnaires were completed at the seminar venue and participants were asked to answer them without discussion with their partner. They were given unlimited time to complete them.

The questionnaire consisted of 13 questions, most of which were open-ended. Topics covered included how participants learnt about the seminar, what their expectations of the seminars were, what the most important aspects of the seminars were and what they felt was required to destigmatize DI in Germany. Demographic information was also ascertained. As this information was part of an evaluation of the programme, it was not seen as research and therefore not submitted to any Ethics Committee for approval. All participants gave their consent to the results being used in professional publications.

#### Methods of analysis

The data were subjected to qualitative and quantitative analysis and additional insight was gained by using triangulation across the qualitative and quantitative analyses. Comparisons on the key dimensions of the study were drawn from the data, particularly with respect to the impact of

infertility and internalization of feelings, which were thought to contribute to the development of stigma. A qualitative protocol was developed to identify key factors on the impact and development of stigma contributing to the marginalization of respondents. Thematic and discursive methods of analysis were used to analyse the construction of meanings inherent within the data, and to identify and generate understanding of the key discourses, which are thought to be used when constructing meanings in relation to stigma.

#### Results

Quantitative data covering the response rate and selected socio-demographic characteristics of the sample are presented (Table 1). The main findings are presented under the following headings: socio-demographic information, expectations of seminars, experiences of seminars and views and perspectives of DI, and these results include both quantitative and qualitative data.

#### Expectation of participants

Two dominant reasons were given for attending the seminars, the need to obtain information (57, 86%) and to enable discussion and sharing with others (56, 85%). Participants wished 'to meet people with the same interests [and] share with them, to clarify whether this is the right way to proceed, to get more fundamental and current information', and to 'gain knowledge about DI, manage my infertility better, [to understand] how men who are the father but not the progenitor think and feel'. One participant clearly indicated the lack of information available on DI: 'As there are few sources for information, I wanted to get as much information as possible.' The seminar was seen as a vital source for gaining information on the subject.

Most participants stated that discussions with other couples considering or undergoing DI treatment was an expectation of the seminar (56, 85%), as reflected in statements such as 'I need to get to know other couples facing the same problems' and '[I] wanted to get to know other perspectives and views'. Attendance was seen as a means of overcoming the lack of opportunity before the seminars to meet people in the same situation and a desire for continuing contact (11, 17%) with participants after the seminar. A self-help group that would promote in public the interests of families using DI was established after one seminar.

Eighteen participants (27%) reported that they expected that attending the seminar would assist them in reaching a decision regarding the use of DI or some aspect of the management of DI, saying, for example that they '... wanted to reduce my anxiety', '... to find out if this method is really the appropriate one for us', '... to get confirmation for my insecure feeling', '... to feel safer', '... to get new ideas for dealing with this topic'. Five participants (8%) expressed a desire to reduce their feelings of helplessness and to have more confidence and faith in their decision to tell the child about the DI origins of their family.

#### Experience of the seminars

Most (45, 68%) participants reported that their feelings of isolation had diminished as a result of attending the seminar,

reporting, for example, that talking with others in similar situations was empowering; typical quotes were 'I was able to find out how others deal with this taboo subject' and 'It was good to be amongst other couples with the same difficulties'.

The division into two gender-based groups on the second day of the seminars was reported to be helpful in assisting participants to share more personal and intimate matters. Two men and three women (8%) commented how important it was to have one group reserved for men only in order to share issues such as male infertility, male self-esteem, and managing male and female coping mechanisms. The helpfulness and value of the seminars was expressed in comments such as '... men were able to discuss amongst themselves' and 'Other men feel just like me! You are not alone with this problem'.

Discussions involving the sharing of experiences with other couples were important for many (44, 67%) participants, who wrote, for example, that: '... to get to know couples facing the same problems', '... to get to know other perspectives and views', '... to find understanding from others', and '...curiosity to meet others' was very valuable. It is apparent from the data that many couples had little or no opportunity before the seminar to get to know other couples using DI or to share their feelings about DI within their normal social network. Statements made during the seminar supported this finding, and one participant reported that 'I can't believe that there are so many others who are in the same boat. I always had the impression we were the only couple doing DI and I had nobody to talk to about my feelings'.

During the seminars, families who had been able to share their choice of family building with their children were able to impart their experiences to others. Participants commented how valuable it was '... that there was a couple who had children with DI and that they talked about their experience' and '... [to have an example] of how and when to tell my child.' Having 'real-life, first hand experience on this matter' motivated some (11, 17%) couples to feel more confident about their abilities to talk openly about this issue.

The effect of normalizing discussions about DI, listening to other experiences and shared learning contributed to respondents ability to share topics that were previously considered too challenging and taboo, and was considered helpful for participants in their journey to find ways of managing these issues. One woman described that, as a result of her discussion, she felt that her dependency on the doctors was alleviated and several other (9, 14%) attendees stated that forming a self-help group, and thus promoting in public the needs of families using DI, would be their way to combat the taboo associated with DI, commenting that '... the meaning of promoting publicity became very important' and '... that IDI [initiative donor insemination] will exist'.

### Views and perspectives of donor insemination in Germany

Twenty-eight (42%) participants believed the lack of social acceptability of using DI as a means of family building demanded public and media attention. Concern about DI remaining a 'taboo' subject was reported by participants (18, 28%) as the reason they could not discuss the matter openly. This matter was reinforced by the attitude of some professionals.

One couple reported that 'We were told by our gynaecologist that DI is not practised in Germany and that we would have to go abroad if we wanted to do it at all. We were given the feeling that it was not morally acceptable to do DI at all and we therefore did not have the courage to question the doctor any further.' Twenty (30%) participants suggested that doctors needed to be well informed about DI and 5% suggested that doctors should refrain from promoting their own moral views. These comments were felt to be especially significant as doctors were seen to be the pivotal professionals dealing with couples who sought assistance in family building. Furthermore, concern was expressed by several participants (16, 24%) that the lack of legal clarity concerning DI contributed to the uncertain social status of the practice.

Anxiety about acceptance within their social networks was expressed by participants; 'There is a yuck-factor attributed to DI which makes it impossible to talk about it in a neutral or even positive way', as one woman said. Six (9%) participants expressed gratitude for the fact that the seminars provided a 'protected environment' in which these matters could be discussed, but 30 (45%) participants felt this was not enough and that attempts should be made to alter the 'culture' surrounding DI, '... to broaden the acceptance in society' and '... work to reduce prejudices'.

Finally, the final hurdle perceived by participants to combat the taboo associated with DI would be an increase in public awareness. It was felt that such a breakthrough would result in more societal acceptance and increased tolerance for families formed by DI. Such hopes indicate that participants considered DI to marginalize them and that these feelings of stigmatization need to be given attention.

### Discussion

The secrecy surrounding DI in Germany (as in many other countries) is reflected in the lack of resources and information. Access to information was one of the main reasons given by participants for wanting to attend the seminars. Getting to know others in the same situation and sharing information and experiences with them was considered of similar importance. The results of the present study indicate that sharing with others is a powerful and helpful way to reduce feelings of marginality and stigma. The seminars aided the process of normalizing the use of DI in building a family and helped to openly acknowledge and manage some of the differences that families resulting from DI experience. The differences seem to become less threatening when there is time and space as well as the incentive to discuss them and when couples realise that others share the same problems. The group setting contributes significantly towards breaking through the circle of secrecy and shame. The traditional counselling setting with individual or couple counselling would not provide the opportunity for immediate feedback from others and would not deal as effectively with the feelings of isolation referred to by most participants.

Inviting to the sessions a family who was willing to share their experiences in being open towards the children and others about DI was a further important factor towards normalizing DI. Participants were exposed to a role model and given the opportunity to explore the relevance of this model for themselves.

One of the aims of some participants was the promotion of public awareness on DI as this was seen to be a major contributor to social stigma. As a result of the seminars in 1999, the self-help group 'IDI – Information Donor Insemination' was initiated. In addition to this national group, a regional group has been established in the Frankfurt area. This smaller group meets on an irregular basis with their focus on providing exchange and support for each other. Other participants who do not live in the area have developed informal links with each other. One of the couples involved in the national group has talked about their family situation on several occasions in the media, thus contributing in public towards greater awareness of this type of family. This national group provides regular meetings, disseminates an information leaflet, has created a website and is currently writing a book for parents who want to share the DI-conception with their child.

Empowering a marginalized group, the main aim of the seminars, seems to have been achieved. Further effects of the seminars were a better understanding of issues surrounding DI and improved reciprocity between professionals in DI service provision. The professionals invited to present at the seminars were able to gain a better understanding of the impact of their roles in infertility care and DI service provision. The involvement of these professionals had a two-fold impact. First, the involvement of a doctor led to interest from the German doctors' association on DI (Arbeitskreis fuer donogene Insemination e.V.) in exchanging professional experience and attitudes about DI, which may lead to closer collaboration between the medical and the psychosocial professionals. Second, participants found it easier to challenge or question the professionals in the group situation compared with a surgery setting in which they might feel less able to ask questions. This was also a new situation for the professionals who encountered for the first time a large group of couples with challenging questions. Normalization and legitimacy of DI, an acknowledged aim of the participants, is one shared by professionals working in this area (Neidert, 1998; Thorn and Daniels, 2000; Guenther and Fritzsche, 2001). Seminars of the type described in this article can contribute significantly towards this development.

## Conclusion

Infertility and the use of DI in particular continue to be considered shameful and families formed with the assistance of DI still often feel marginalized. This article reflects the growing realization by those intending to create their families using DI that they no longer have to feel shameful and marginalized. The number of couples who were able to attend the seminars was low and reflects the obstacles that remain to be tackled. However, the fact that the seminars occurred and will continue to be developed is significant. Marginalization will only ever be eliminated through the legitimacy and equality of DI families. The results of these seminars and the positive responses of the participants indicate that this type of educational and supportive programme is perceived as very valuable and may form the

basis of a model that can be used in the preparation of all people using third party reproduction.

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