

The I'm-Perfect Fathers Group: A Gathering of Fathers of Children with Disabilities

Raviraj Shetty¹, Jehanzeb Baldiwala², Tanya Vasunia³

Abstract

Objective: The objective of the study was to explore the impact of sharing experiences of fathering by creating a support group for fathers of children with disabilities using narrative frame of reference.

Methodology: The participants were fathers of children with disabilities selected through pre-defined criteria. The group was conducted over six 2-h sessions held once a week. The group was cofacilitated by an occupational therapist and a father. The facilitator used the narrative frame of reference to support discussions around themes of fathering in each session. Post-intervention, a focus group was conducted to assess outcomes. The focus group was documented by audio and video recording devices. Thematic analysis was used to analyze data for emerging themes and to understand outcomes.

Results: Primary themes that emerged were (a) learning from each other's experience, (b) redefining disciplining, (c) navigating through fatherhood, (d) the benefits of a nonjudgmental space, and (e) advocacy.

Conclusion: The findings identify fathers' need for a space to share their narratives of fathering a child with disability. The study also demonstrates the need for therapists to engage fathers in the process of family-centered care and indicates that involving fathers could lead to better outcomes for families.

Key Words: Developmental Disabilities, Occupational Therapy, Pediatrics, Stories

¹Senior Occupational Therapist & Training Lead, Ummeed Child Development Center, Mumbai, Maharashtra, India,

²Director of Mental Health, Ummeed Child Development Center, Mumbai, Maharashtra, India,

³Research Assistant, Ummeed Child Development Center, Mumbai, Maharashtra, India

Place of Study

Ummeed Child Development Center, Ground Floor, Mantri Pride 1 B, 1/62, N. M. Joshi Marg, Subhash Nagar, Lower Parel, Mumbai - 400 011, Maharashtra, India

Period of Study

January, 2015 - December, 2015

Correspondence

Raviraj Shetty, Ummeed Child Development Center. Ground floor, Mantri Pride 1 B, 1/62, N. M. Joshi Marg, Subhash Nagar, Lower Parel, Mumbai - 400 011, Maharashtra, India.

Tel.: 022-65564054/
022-23002006,

Mobile: +91-9819441833,

Email: ravirajshety@gmail.com

Paper was presented at OTICON'2016, the 53rd Annual National Conference of AIOTA at Chennai, Tamil Nadu, India, in AIOTA Trophy for Best Paper in Mental Health.

INTRODUCTION

Fathering occupations are identified as a significant aspect of men's lives where fathers describe meaningfulness of occupations ranging from extraordinary journeys to the ordinary everyday activities of bathing, feeding, and doing math problems together.¹ A recent systematic review of studies which controlled for maternal involvement and gathered data from different independent scores found "positive" father involvement associated with a range of desirable outcomes for children and young people.²

Substantial research, however, shows these fathers being ignored or dismissed by services and variously described as "the peripheral parent," "the invisible parent," and "hard to reach."³⁻⁶ Dollahite states that father's involvement is not well understood due to myriad reasons including historical focus on mothers and the understanding that father's role is secondary by many care providers.⁷ Moreover, the traditional patriarchal Indian culture expects a father to be affectively distant and a stern disciplinarian.⁸ These beliefs create a stereotype of fathers as distant and disengaged figures.

Giving such fathers' opportunities to discuss their concerns with each other could help decrease their sense of isolation, foster a sense of agency and community.⁸ Research has shown the importance of support groups when cultural norms and gender stereotypes make it difficult for individuals to reach out for help.⁹

Accordingly, a support group structure was used to create an opportunity for fathers of children with disability in an Indian context to explore their understanding of and diverse enactments of fatherhood. The support group described in this paper was guided using the narrative frame of reference with an understanding that our lives are shaped by the stories we create.¹⁰ The frame of reference invites people to tell or retell stories about the challenges and problems they encounter in their lives as well as the skills they are using to respond to these problems. The therapist within the narrative frame of reference is a curious listener of these stories and influences the development of these stories through questions and reflections.^{11,12}

Thus, the objective of the study is to explore the impact of a support group guided by the narrative frame of reference on the fathers of children with disabilities.

METHODOLOGY

Study Design

This was a qualitative phenomenology- based study.

Participants were selected from the center's pre-existing database. Participants were initially contacted through email. Those interested were provided more details telephonically. Of 20 fathers initially approached, 10 expressed interest and 6 joined the group.

Participants were selected based on following criteria:

1. They had to be fathers
2. They had to have at least one child with developmental difficulties
3. They had to be proficient in English.

Ethics and Logistics

Care was taken to ensure confidentiality so that participants felt comfortable and safe within the group. The project was designed with supervision from the director of the mental health team. Each participant was provided with a consent form that provided detailed information regarding the use of the data and confidentiality measures.

Procedure

Once the necessity for the group was established, a semi-structured outline of the group objectives was created. The group sessions were held on Saturday afternoons for 6 weeks. The duration of each session was 2 h. After the first session, which began with introductions, each weekly session started with reflections fathers wished to share with each other. This was followed by a semi-structured question which had been created before the session within a supervision setting (Appendix A). Questions were designed to facilitate discussion and reflect on experiences. The questions were designed with the intention to develop stories of their skills, knowledge, hopes, and problems as fathers.

The discussions were scaffolded using additional questions, activities, presentations, images, and videos. The group was facilitated by an occupational therapist and cofacilitated by a father who was recruited through an interview process conducted by the lead author. After six sessions, a focus group that explored the impact of the group on the participants was conducted by the second and third author.

Data Analysis

The focus group was audio-recorded and transcribed verbatim by the third author. Transcriptions contained accurate accounts of narrations inclusive of repetitions, pauses, and hesitations. The analysis was based on the semantic content of the interview. A deductive thematic analysis took place based on the area of research and the nature of the data.

RESULTS

The five major themes that were derived from the thematic analysis of the data from the focus group were as follows:

1. Learning from each other's experience
2. Redefining discipline
3. Navigating through fatherhood

4. Benefits of a non-judgmental space
5. Advocacy.

Learning From Each Other's Experience

Fathers repeatedly reported the importance of hearing other fathers' experiences and learning from each other. They talked about occupations that other fathers in the group were doing which influenced their fathering and created possibilities for new occupations that supported their fathering.

D: So when R presented about a journey that he and his son took. It was a trip that he and his son took together to the U.S. Right. And what came out was that characteristics uh, of, uh, of his son. The characteristics in Bombay versus in that journey were dramatically different, right. So, an environment change, you know, uh, it just came out that he was more self-disciplined.

R: There was the fact that whenever you know, try and raise the curiosity of the child, even with mundane daily things, that you know, you are driving down. I think that you were mentioning, *gestures to D* was that why is it more necessary to, to, uhh, drive slow in the rain. And, and you just make the child think. I have not started implementing that yet. So one thing that I need to do is, you know try and do that. Try and figure more interaction with my son. Instead of sitting back and being quiet. So, that's another lesson to take away for me.

D: "Choose your battles." Has really struck up a chord across, even the five, all the five of us when we were there. You can't win all of them There is no point in winning all of them. So, that was one major learning across the group.

The above quotes highlight the impact and value given to each other's narratives. Information and ideas were transferred between participants through these narratives. The idea of "choosing your battles" became a mantra for the fathers in challenging times.

Redefining Discipline

This particular theme has strong links with Indian culture and the stereotypes surrounding masculinity. The idea of physical discipline, masculinity, patriarchal hierarchy, and fatherhood was intrinsically linked for some participants. Through discussions in the group, these ideas were unpacked and many fathers reexamined their ideas about discipline and its effects within the context of the father-son relationship.

Few quotes which highlight this were as follows:

D: So it is not necessary, one need not be very impatient for things to happen. So, for instance, I think one of my takes was that, so when my son was diagnosed uh, with autism. And uh, we started work on that, right. I was kind of an impatient guy. So, for me, it was a fine balance between hitting him and disciplining. And disciplining for me could get physical, right. So, giving him two whacks. Because of it, for me, it was also about popular perception, right. How he behaves himself when five people come. So, I can live with his hyperactivity. But, people are going to judge him. So, I wouldn't shy from giving him a whack saying, "Don't." I was always trying to figure out

that fine balance between treating him individually. But, I will also whack him individually. So that, I am setting the rules. After the father's group, you know, I've just stopped hitting him or even reprimanding him very very harshly. Because when I heard, you know, R speak about his kid.

R: Violence is not going to. First of all is not good idea with anybody. Particularly not with these kids because, um, you know you, can hit somebody, and reprimand him. And hope to correct that mistake if they did it intentionally or did not pay attention to... Suppose he's done something to reprimand him and he does it again. He's done it intentionally. You reprimand him. You hit him. Maybe he is going to change. But, some of the challenges that our children have...is, is, is you know, he may repeat that mistake involuntarily.

P: For, for me, complete stopping, was a result of this group. I never thought that I was on the wrong path. I might not have taken such a radical approach of, not, matlab, minimizing my whacking to 99% you know, down. Had it not been a part of this group. We figured out that there were different approaches.

The realization that repeated mistakes may be a consequence of their children's disability marked a turning point in participants understanding of discipline. After this reexamination, many fathers reported a difference in their relationships with their children. They noted that they were able to find creative ways of disciplining rather than using physical methods which lead to a relationship filled with conversations, laughter, playfulness, and understanding.

Navigating Through Fatherhood

This theme was prevalent from the beginning of the group. Many fathers recalled in the focus group that they had enrolled simply to see if they were fathering "correctly."

Navigating through fatherhood can be considered an overarching theme. The group was brought together by their quest to understand what makes a perfect father. Each dilemma and situation which was discussed by the fathers helped them reflect on and embrace their journey of fatherhood. Some of these are illustrated in the quotes presented below:

R: "But where I think it changed, was with D's presentation where we started talking about our own children and our journey with them. You know. And, uh, D did, then I did, then P did. And, we suddenly realized that it's not about question and answers. It's about learning on the go."

P: Patience on the journey. I mean, I, uh, I never spoke about this. But, I just simply felt that consistently, all of the three of us have just. Whether we were violent, or whether we were, uh. At least we had the good intentions. But, we did not carry it through. And patience was the biggest vehicle on which you're supposed to, drive on. And all, all three of us have just realized we need more and more patience with ourselves and with the relationship with our children.

Benefits of a Non-judgmental Space

Having a non-judgmental space was another major theme that emerged from the focus group. To have a space where fathers can share their experiences without judgment was described as imperative to the group's functioning. This allowed the fathers to share their fears, worries, and mistakes openly.

As P says, "It's not that the father does not want to get involved. A father wants to get involved but doesn't know how and what we tried to do in this group is that just learnt the fact that every body is wanting to kind of, you know. The father is positive. And by default it is negative. Okay. Just they don't know how. They don't say. Don't know how to do it. Here is a space where we spoke to each other. Means here, I spoke more than whatever I speak at home also."

This non-judgmental space also allowed participants to discuss both their preferred stories and problem stories.

R: See, uhh, I guess, the, basic thought was that, I was hoping to be a good father is...is what I was searching for. After coming here, I realized everyone is on the same path. So, I started enjoying the journey.

This non-judgmental space became an important step toward the group's collective narrative. This theme helped the participants realize that "At the end of the day, we are all in the same boat." Fathers were able to discuss what "being a father" is about and to come to terms with the fact that there is no such thing as a perfect father. A few of the quotes from fathers that support this theme are as follows:

P: Uh, no. Not hoping for. But, well, I was hoping for "being a father." "How to be a good father," or "What are the experiences of being a good father."

D: Speak about ours, about the mess that we are in.

Advocacy

The fifth theme that emerged was advocacy. This has significant implications for the group's progress. The ability to look at the macro rather than the micro suggests a shift in thought process and ideology.

D: You know, certain, some of our learning was, could be shared. You know, could be adapted, adopted by the other fathers.

R: You know, apparently you are targeting the mothers only. Primarily, the mothers. But, if the mothers are doing it correct, the fathers are screwing up. Sorry to use the word. That's half the battle lost. So, you need to get the fathers. You need to get the. You need to encourage the fathers to get their act correct. You know, if you really want the children to flip.

Advocacy, in particular, displays the ability to create a different type of narrative.

When the group discussed how fathers need to be targeted more, it was an example of how important advocacy is for

the group's ability to look back and learn from each other's experiences and journeys.

While discussing their journey as a group, one of the fathers commented on how this group was history. This observation is powerful given that this was the first father's group in the history of the center.

DISCUSSION

The discussion in this paper centers on highlighting the processes that supported the themes that emerged through linking of lives of fathers. The findings of this exploratory study clearly identify fathers' need for a space to share their narratives of fathering a child with disability. Using narrative frame of reference made it possible for the group to explore the fact that the fathers are constantly using creative ways to overcome some of the problems that are posed by the disability in their child's life.

The narrative frame of reference's aim is to focus inquiry on alternate stories or ways of responding that are separate from problem stories.¹³ This helped guide discussions focused on ways that fathers were responding to their children and steps they were taking to build relationships with them rather than focus on stress/coping. Sharing stories helped fathers recognize that their intentions for having positive relationships with their children were being respected and they could discuss hopes for their children, some of which were shared by other fathers. Linking lives in this way can support creation of connections that can be viewed as what Stern called, "shared feeling voyages, a process whereby moments of meeting with others create experiences that are personally undergone and lived through the present." Shared feeling voyages open new possibilities by putting in question the established nature of relationships which may not be a complete truth.¹⁴

The second important aspect was that the therapist maintained a position of curiosity, staying de-centered yet influential. This refers to a position where professional knowledge does not form the center of the learning. Rather what remains at the center of the support group are the skills and knowledge that the fathers bring to enacting fathering and their unique hopes and intentions for their roles as father. The therapist is influential in this process through the use of questions that uncover skills and knowledge that fathers already have which can be used to address the current concerns.¹⁵

As a result, this group collectively expressed a desire to move toward more individual parenting and disciplinary methods that were responsive to their child's unique needs. One of the outcomes that resulted from this was that the fathers came together to redefine what discipline meant to them, how they would like to perform this occupation going ahead and the stand to refrain from physically disciplining their children.

Another process that facilitated the themes to emerge was having the father of a child with disability as a cofacilitator in the group. Inviting a father of a child with disability to cofacilitate the group contributed toward creating a safe, non-judgemental

space in the support group. His having similar lived experience ensured that space remains free from "professional judgment" and that fathers feel safe to share feelings of doubt, mistakes, or raise any questions. This gave fathers the opportunity to share diverse enactments of fatherhood.

What also emerged from this combination of the therapist's de-centered position and the presence of a peer consultant fits with Bonsall's description of advocacy where fathers move from extending the enactment of fatherhood from caring for his own child to caring for children in general.¹ The fathers through their sharing came to the agreement that what they had learned was relevant and could be shared with a wider group of fathers parenting children with disabilities. These could be "adapted and adopted" by the other fathers and become a way to further way to link lives around shared experience. As described by one of the participants, "every father should be given an opportunity to think about what the disability means for his child and to clarify what he understands. A chance to understand what his contribution to the child's journey can mean and the importance of this for the child's development would be a significant start for most families."

CONCLUSION

We conclude that creating a support group for fathers of children with disabilities using the narrative frame of reference helps fathers have agency, a sense of community, and reduced isolation, thus participate in their child's development.

Despite the fact that the sample in this study was limited to six fathers of children with disabilities who were from an urban English-speaking context, for therapists and professionals working with children with disabilities, the group highlights the importance of engaging fathers in the therapeutic journey of children with disabilities.

There is scope to further explore the journeys of fathers from non-English speaking, rural, and lower socioeconomic contexts. One of the hopes for sharing this work is that the ideas shared and the themes that emerged might interest occupational therapists in India to provide similar platforms and opportunities to fathers.

ACKNOWLEDGMENT

We would like to thank Dr. Vibha Krishnamurthy, Medical Director, Ummeed Child Development Center, for encouraging us to explore newer clinical territories. Special thanks to the fathers participating in the group for allowing us to share their journey of fathering.

REFERENCES

1. Bonsall A. Fathering occupations: An Analysis of Narrative Accounts of Fathering Children with Special Needs. *J Occup Sci* 2013;21:504-18.
2. Pleck JH, Mascadrelli BP. Paternal involvement by US Residential Fathers: Levels, Sources and Consequences. In: Lamb ME, editor. *The Role of the*

Father in Child Development. 4th ed. Hoboken, NJ: John Wiley & Sons; 2004. p. 222-71.

3. SCIE Research Briefing 18: Being a Father to a Child with Disabilities: Issues and What Helps. Available from: <http://www.scie.org.uk/publications>. [Last cited on 2015 Aug 10].
4. Lamb ME, Laumann-Billings LA. Fathers of Children with Special Needs. In: Lamb ME, Editor. The Role of the Father in Child Development. 3rd ed. New York: John Wiley & Sons; 1997. p. 1-18.
5. McConkey R. Early Intervention: Planning Futures, Shaping years. *J Appl Res Intellect Disabil* 1994;7:4-15.
6. Herbert E, Carpenter B. Fathers - The Secondary Partners: Professional Perceptions and Father's Reflections. *Child Soc* 1994;8:31-41.
7. Dollahite DC. A Narrative Approach to Exploring Responsible Involvement of Fathers with Their Special Needs Children. In: Day RD, Lamb ME, Editors. Conceptualizing and Measuring Father Involvement. 1st ed. Mahwah, NJ: Erlbaum; 2004. p. 109-27.
8. Bristol MM. Family Resources and Successful Adaptation to Autistic Children. In: Schoipler E, Mesibov G, editors. The Effects of Autism on the Family. 1st ed. New York: Plenum Press; 1984. p. 289-310.
9. Solomon M, Pistrang N, Barker C. The Benefits of Mutual Support Groups for Parents of Children with Disabilities. *Am J Community Psychol* 2001;29:113-32.
10. Carey M, Russell S. Re-authoring: Commonly asked Questions. *Int J Narrat Ther Community Work* 2003;2:67-91.
11. Mattingly C. The Narrative Nature of Clinical Reasoning. *Am J Occup Ther* 1991;45:998-1005.
12. Clark F. Occupation Embedded in a Real Life: Interweaving Occupational Science and Occupational Therapy 1993 Eleanor Clarke Slagle Lecture. *Am J Occup Ther* 1993;47:1067-78.
13. Morgan A. Beginning to Use Narrative Therapy. *Int J Narrat Ther Community Work* 2002;2:85-90.
14. Stern DN. The Present Moment in Psychotherapy and Everyday Life. New York: W.W. Norton; 2004.

How to cite this article: Shetty R, Baldiwala J, Vasunia T. The I'm-Perfect Fathers Group: A Gathering of Fathers of Children with Disabilities. *Indian J Occup Ther* 2017;49(1): 29-33.

APPENDIX A

Session number	Question/topic of discussion
1	What are some of the hopes you have as we go along the six sessions? How would you describe your child, the way you want him to be known by people around you?
2	What are the things you do together that makes both of you happy and engages him with you?
3	What are some of the ideas you have around disciplining?
4	“Being the perfect father”
5	“Is it my child or is it the disability”
6	What are some of the learning from this group sessions? How do you see yourself using them in the future?