The Perspectives and Experiences of Parents of Children with Down syndrome: Information Sharing

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Introduction

• Parents of children with Down syndrome have a right to full, accurate and timely information sharing from health professionals

• Generally families receiving a diagnosis do not have much information or have poor information or attitudes

• Guidelines for practice are available for health professionals to use

• Information sharing is a critical element to timely and professional service delivery

• Information should be shared with parents in order to best provide early intervention services
Information sharing

- Information sharing is the process of information exchange between two parties

- In South Africa there is a discrepancy between public and private health care sectors which subsequently affects the information sharing process

- In South Africa, service provision is generally guided by the principles of Batho Pele.
What has been said before?

• Parents felt that there was a need to enhance information shared and reported the lack of written material

• Parents expressed a need to receive information regarding a definition, the cause, and implications for family

• Parents felt they received insufficient information regarding communication development

• Intervention should begin within the home environment
Why do this study?

• Initial contact with health professionals will have a significant impact on all following interactions

• Parents should have sufficient information shared for their needs at specific stages

• There is a gap in the knowledge about the information sharing process within South African context

• It is important to find out how parents experienced information sharing so we can improve health services
Why do this study cont.

• No studies of this nature, within the South African context and specifically within KwaZulu-Natal, were found

• We come into this from a speech-language therapy background. We are one of a number of health professionals families of a child with Down syndrome come into contact with, our services are affected by the information given by others and thus we wanted to find out about the “general” information sharing and about aspects related to communication and feeding
How was this study done?

Aim:
• To explore the perspectives and experiences: information sharing

Objectives:
• To explore the experiences and perspectives: information and how it was shared
• To explore the experiences and views: professionals referred to after diagnosis and the information shared
• To explore the experiences and views: Speech-Language Therapist and information shared
How was this study done cont.

Study design:
• This was a qualitative study focussed on asking people about their experiences rather than a study on many people giving “numbers”

The people who took part were:
• Parents of a child with Down syndrome
• Children with Down syndrome were between the ages of 18 months and 5 years of age
• Parents lived in the eThekwini region of KwaZulu-Natal, South Africa
• Children had a diagnosis of Down syndrome only
**How was this study done cont.**

Participant description:

<table>
<thead>
<tr>
<th>Participant</th>
<th>Relation to child</th>
<th>Child’s age</th>
<th>Age of Diagnosis</th>
<th>Private versus Public services</th>
<th>Speech-language Therapist</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Mother</td>
<td>1;9</td>
<td>Birth</td>
<td>Private</td>
<td>√</td>
</tr>
<tr>
<td>P2</td>
<td>Mother</td>
<td>2;11</td>
<td>7 months</td>
<td>Private</td>
<td>√</td>
</tr>
<tr>
<td>P3</td>
<td>Mother</td>
<td>3;0</td>
<td>1 year+</td>
<td>Public</td>
<td>√</td>
</tr>
<tr>
<td>P4</td>
<td>Mother</td>
<td>5;6</td>
<td>2 years</td>
<td>Public</td>
<td>√</td>
</tr>
</tbody>
</table>
How was the study done cont.

• An interview schedule was used:
  • Information given at point of diagnosis
  • Information given post diagnosis
  • Professional referral system
  • Experiences and views of the speech-language therapist
# Results and Discussion

<table>
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<th>Themes</th>
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<td>1. Implications of a late diagnosis</td>
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<td>2. Parents’ perspectives on information shared</td>
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<td>3. Accessing of alternative means of support</td>
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<td>4. The quality and content of information shared: General versus Specific</td>
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<td>5. Referral procedures: Timing and the professionals involved</td>
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<td>6. Private versus public health care</td>
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<td>7. Parent satisfaction and action toward information shared</td>
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<td>8. Experiences with the speech-language therapist: Perspectives on the information shared</td>
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</tbody>
</table>
**Results and Discussion cont.**

*Theme 1: Implications of a late diagnosis*

Late diagnoses were given to two mothers. One mother received a diagnosis immediately after birth. The other diagnoses were made during the first week after birth (P4), at seven months of age (P2), and at two years (P3).
Results and Discussion cont.

• At diagnosis mothers were not given in-depth information
• When compared to literature it is evident that information was inadequate
• Doctors did not seem to follow set guidelines regarding the principles of truth-telling

P3 L3 “She only told me that Down syndrome is not a disease, but it’s a...can you say, it’s a...condition.”
Results and Discussion cont.

Theme 2: Parent’s perspectives on information shared

- Dissatisfaction with a doctor and the information he shared.

- Results suggest that doctors require training regarding information sharing

P1 L12 “Her (participant’s child) IQ is going to be at a certain point and I thought oh ok screw you, you don’t know my daughter.”

P1 L14 “I think at the beginning, I think initially, I think people need to be a bit positive as well.”
Results and Discussion cont.

Theme 3: Accessing alternative means of support

- Majority of support came from another mother who had a child with Down syndrome
- Remaining mothers were not provided with a wide variety of support options
- Onus placed on the South African health care professionals to equalize the standard of information sharing

P2 L9 “Yes, I didn’t get referrals, I found the people myself.”

P3 L4 “My madam helped. She even went to the computer to check, to find out what is a Down syndrome.”
Results and Discussion cont.

Theme 4: The quality and content of information shared: general versus specific

• All mothers indicated that information appeared to be too general in nature

• A mother raised the issue of a lack of information about early intervention

P1 L13 I’m talking specifically from my point of view right, I think people are too general I really think people are too general.”
Results and Discussion cont.

Theme 5: Referral procedures: timing and professionals involved

• Mothers who accessed private health care services were referred to a wider range of professionals

• Referral system one is included in, is dependent upon the professional

P1 L13 I’m talking specifically from my point of view right, I think people are too general I really think people are too general.”
Results and Discussion cont.

**Theme 6: Private versus public health care**

- Information shared with mothers who accessed the private health sector was more informative, relevant and applicable to the situation.

- Mothers who accessed public services were provided with less, generally negative information, and little practical guidance was provided.

> P1 L22 “Every two weeks I went to see her surgeon, ok this medication is working, this medication, this treatment is not working.” *(Mother referring to gastro-intestinal specialist)*

> P3 L7 “She has to be patient, ‘cause it’s very difficult to handle this child when he is a Down syndrome.”
Results and Discussion cont.

**Theme 7: Satisfaction and action toward information shared**

- Mothers may not be aware of what information they should be seeking out
- Mothers not aware of what standard of information they should receive
- Professionals appear to have limited knowledge as to what and how information should be delivered

P3 L2 “In my knowledge, I don’t know if it’s anyway I can say better, ‘cause I don’t know nothing. I just take whatever they telling me and try. If it’s anymore I'm willing to take that knowledge with her health.”
Results and Discussion cont.

Theme 8: Experiences with the speech-language therapist: perspectives on information shared

- All mothers felt that the information they received from the speech-language therapist was positive and adequate
- Minimal information about feeding, hearing and communication stimulation provided
- Compared to literature inadequate information has been shared with these parents who accessed services in both the public and private health care sectors

P2 L50 “She’s been the best help that I could have had.”
Selected Implications

• Speech-language therapists need to advocate and promote their role within information sharing with the Down syndrome

• Speech-Language therapists should advocate the implementation of early communication intervention services for those with Down syndrome in South Africa

• The type and quality of information provided needs to be monitored
**Selected Implications cont.**

- Guidelines are available and should be used

- Health professionals need further training in what information to share, when and how. Online Continuing Professional Development may be an option

- Families should be empowered, supported and respected in their right and quest to accurate, full, timely and sensitively shared information
Conclusion

• Significant discrepancy in information sharing process when compared to international standards

• Responsibility falls on parents to access necessary information and services

• The professional sharing information and its quality and relevance influences services accessed by parents of children with Down syndrome and thus the outcome and achievement of the person with Down syndrome
Acknowledgments

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References

References cont.


• on 14/09/2011.
References cont.


Thank You

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