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“We don’t like talking about toileting issues in front of everyone”: Parents’ reflections on family-centered care

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Recommended Citation

Ruiz, Holli, "“We don’t like talking about toileting issues in front of everyone”: Parents’ reflections on family-centered care" (2019). *OT Student Capstones*. 46.

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Introduction

Research has indicated that there is a disconnect between the literature on the enactment of family-centered care and what is actually occurring between families and healthcare professionals.

Family-centered theory is based on the importance of the family in a child's well-being and care.

- Family is the constant and strength in the child’s life.
- Family is the expert in what is most appropriate for them.
- Respect the diversity and cultural differences of each family.
- Acknowledge the significance of the family in the decision making process for their child.
- Family is not dependents of the client.
- Establish a partnership. (Bamm & Rosenbaum, 2008; Lawlor and Mattingly, 2013; Jaffe and Cosper, 2015)

Methods

The purpose of this study was to describe how pediatric occupational therapists enact family-centered care in the outpatient clinic and families’ perceptions of this care.

- Research took place in a pediatric outpatient clinic.
- There were 21 participants who were the parents of children receiving occupational therapy services at the clinic.
- Participants filled out open-ended surveys consisting of six questions.
- Survey answers were organized into an excel spreadsheet.
- Answers were analyzed using thematic coding.
- Two researchers coded answers separately utilizing colors to identify themes.
- The researchers met to compare and contrast coded themes.
- Themes were continuously revised to develop 5 common themes.

Table 1: Themes

| Theme | Example |
|--|--|
| Styles of Communication (37 responses) | <p>Listening:</p> <ul style="list-style-type: none"> • “The therapist have been so amazing at listening to my concerns.” <p>Frequency:</p> <ul style="list-style-type: none"> • “Communicate to me at each session” • “Constant communication” <p>Quality:</p> <ul style="list-style-type: none"> • “Great communication” • “Showing family how to incorporate the activities at home.” |
| Transfer to Home (20 responses) | <ul style="list-style-type: none"> • “Better bridge between clinic and home • “Show parents what is being taught so we can implement same steps at home.” • “Showing family how to incorporate the activities at home.” |
| Environment (15 responses) | <p>Privacy:</p> <ul style="list-style-type: none"> • “We don’t like talking about toileting issues in front of everyone.” <p>Viewing treatment sessions:</p> <ul style="list-style-type: none"> • “Invite parents back to see how goals are being worked on” • “I come every week with child and stay with him the whole time” |
| Focusing on the Child (28 responses) | <ul style="list-style-type: none"> • “Most of the care is focused on my son who is the client...” • “The therapists work so well with my son.” |
| Involving the Family in Goals and Focus (39 responses) | <ul style="list-style-type: none"> • “Very involved and informed” in the treatment process. • Desire for the therapist to “review goals before setting them” • “Every few months the therapist and I set goals” |

Conclusion

Based on the results:

- Overall, there was satisfaction with the clinic and praise for direct therapy services provided to the child.
- The themes revealed gaps in the communication between the therapist and the parents that parents did not address when initially asked.
- Several parents revealed concerns with the privacy of sharing information in the lobby of the clinic.
- There was an inconsistency in viewing treatment sessions. Some parents reported frequently viewing their child’s therapy sessions, while others expressed the desire to be invited back with their child.
- Parents viewed the “client” as the child and not as the family unit.
- Overall, parents’ answers indicated they were unclear about what to expect in terms of family centered care.

Implications for practice

There are several ways for occupational therapists to improve practice as a result of this study.

- Occupational therapists should recognize and respect privacy in the outpatient setting.
- Increase overall communication with parents and be mindful of possible areas of miscommunication.
- Provide increased education for families on what family-centered care encompasses and what they can expect with this delivery of care.
- Professional development of guidelines for enacting family-centered care.

References

References available upon request.

Acknowledgements

Thank you to all the parents and families who took the time to participate in this research. Thank you to my family for your endless support.