Moving from Parent ‘Consultant’ to Parent ‘Collaborator’: One Pediatric Research Team’s Experience

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BACKGROUND

In our Move & PLAY study, parents
- reviewed the grant applications, provided feedback prior to revision and resubmission
- reviewed all training materials and data collection forms with a view to being sensitive to potential issues with respect to reception by children and families
- participated in interviewer training sessions
- facilitated ‘short titles’ for Move & PLAY and ‘On Track’
- reviewed and refined recruitment brochures and posters
- reviewed and refined feedback forms and newsletters for families
- reviewed and refined all knowledge translation summaries for the Move & PLAY study
- provided permission to acknowledge contributions to study implementation

When we began the On Track study, we identified a document from the UK to be useful in distinguishing ‘consultation’ to ‘collaboration’ (requiring ongoing teamwork and involving mutual appreciation of unique knowledge, skills and experience of each member)

INITIAL RELATIONSHIP: Role of Consultant

- We share our experiences of working with parents in pediatric physical therapy research, describe how our working relationship has transitioned from ‘consultation’ to ‘collaboration’, and propose further enhancements to realize our shared vision
- The seven parents participating in the On Track study shared that they value research participants who are welcoming and who encourage them to express thoughts and share ideas. It is important to parents that their input is valued. Although they are committed to participating in research, finding time is often a challenge in their busy lives.

EVOLVING RELATIONSHIP: Role of Collaborator

- Role of Consultant
  - ‘Consultation’ (requesting review intermittently and asking about the parent – researcher partnership and impacts on our current research, in part through monthly meetings. Evaluation of impact was part of a recent focus group discussion and will be ongoing.

- Role of Collaborator
  - In the INVOLVE framework, elaborated upon by the Australian government, we describe our evolving collaborative relationship and identify where further enhancements can be made to realize our shared vision.

IDENTIFYING AND PRIORITIZING RESEARCH

- People who are affected by research have a right to have a say in what and how publicly funded research is undertaken.

- In both Move & PLAY and On Track, our research questions were generated by our PT team members, based on gaps in PT knowledge to guide collaborative practice.

- Examples of parents collaborating in establishing research agendas, especially relating to the effectiveness of complementary and alternative interventions have been published.

IMPLEMENTING INVOLVEMENT: Involvement of health care consumers can influence, support and strengthen the uptake of research in practice.

- This role has largely been unexplored to date. As we move to planning knowledge translation from our past studies, we will engage in a ‘Deliberative Dialogue’ with policy makers. Parents will be instrumental in assisting with preparation of our briefing notes.

Disseminating

- Involvement of health care consumers enhances widespread dissemination of study results in clear, user-friendly language.

- Parent team members have collaborated in developing knowledge translation summaries from the Move & PLAY study, written commentaries in peer-reviewed journals, and participated in development of conference presentations. In future, they will also participate in key peer-reviewed manuscripts and research presentations. They are proactively providing knowledge translation material from our research study, including submissions to parent magazines and preparation of video materials on how to sensitively communicate diagnostic information.

EVALUATING IMPACT

- INVOLVE recommends monitoring and evaluating the short- and long-term impacts of consumer involvement in research.

- At this time we have initiated informal discussions, sharing perspectives on what and how we are learning about the parent – researcher partnership and impacts on our current research, in part through monthly meetings. Evaluation of impacts was part of a recent focus group discussion and will be ongoing.

COMMISSIONING

- Many funding organizations now involve health care consumers in commissioning research.

- Although not directly a part of the research team, funding from PCORI (the Patient-Centered Outcomes Research Institute) considers the public perspective and requires consumer involvement.

DESIGNING AND MANAGING

- Involving health care consumers in research design and implementation helps to ensure that the research is relevant, acceptable to research participants and feasible to conduct.

- Parent team members primarily functioned as consultants in the design of our studies. The collaborative role is emerging as parents provide complementary advice to help with ongoing recruitment and data collection issues.

UNDERTAKING

- Health care consumers can develop information, conduct interviews, use research tools, and assist in analyzing and interpreting results.

- Parent team members have assisted in writing newsletters for study participants, prepared short web-based communications ‘by parents for parents’, guided us in how to provide ongoing study feedback to families, prepared an exit survey to understand participants’ experiences in the On Track study (what else should we have asked about your child, what are you most interested in knowing about your child, how do you prefer to receive assessment results) and will collaborate in interpretation of the results.

SUMMARY

- We advocate for true collaboration among all team members at all stages of research:
  - Deciding what to research
  - Deciding how to do it
  - Securing funding and ethical approval
  - Implementing the research plan
  - Communicating the results to a range of stakeholders using multiple formats
  - Facilitating uptake in rehabilitation practice
  - Evaluating outcomes of the partnership

- We encourage others to use the resources referenced below to facilitate truly collaborative research teams

ACKNOWLEDGEMENTS

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- Our shared vision is ‘knowledge exchange’ of research-based information to impact child- and family-centered rehabilitation practice to enhance outcomes and lives of children with cerebral palsy and their families

- This goal is best achieved through strong collaborations with consumers at all stages of research

REFERENCES


