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PROPOSED STUDY

PURPOSE & BACKGROUND

The purpose of this board game is to help children strengthen their role as partners in hemophilia care by exploring typical life scenarios and requisite decision making skills. This game is based on study recommendations on how children understand their role in family-centred care of their bleeding disorder (Pritchard, 2008)

Children with and without hemophilia articulated seven key elements required for effective partnerships in their chronic illness care: "my best interests; virtues; talking and listening; being involved; knowing; making decisions; and being connected". One of the children's key recommendations was to create a resource that integrates these elements in game play with others, so that they may work together through typically experienced scenarios, and help children themselves to engage in decision-making as partners in their care.



OBJECTIVES

The primary objective of the study is to explore how playing an educational board game affects school age children's engagement in decision-making processes for their hemophilia self-care.

Secondary objectives include comparing children and parent perspectives regarding how the board game affects engagement in decision-making processes for children's hemophilia self-care, and families' recommendations for future board game development.

STUDY DESIGN

SETTING & SUBJECTS:

Phase I (3 boys 8-12 yrs with hemophilia and their household family members including at least one parent/guardian; compared with 3 boys with cystic fibrosis and their household family members including at least one parent/guardian). This phase will take place within the catchment area served by the Alberta Children's Hospital including southern Alberta and south-eastern British Columbia. Interviews will take place at the Alberta Children's Hospital or at the children's home based on family preference.

Phase II (15 boys with hemophilia and their household family members, including at least one parent/guardian). This phase will take place in Canada and the United States, and includes the catchment area served by Canadian Hemophilia Treatment Centres, and the University of Colorado (Denver), Hemophilia and Thrombosis Centre.

DATA ANALYSIS

Rigour in this mixed method study will be upheld by adhering to *trustworthiness* criteria (Lincoln & Guba, 1985). In phase I, qualitative analysis of written, verbal and observed behaviours reflecting manifest (direct) themes will be used, supported by an open coding frame (Berg, 2001; Marshall & Rossman, 2011). Tool refinement will be assessed by review of questionnaires on coping and decision making, with verbal feedback on how to improve clarity, relevance, and flow to ensure tools are user-friendly. Families will also complete a post-game play questionnaire to evaluate game enjoyment (open & closed items). In phase II, qualitative analysis of written, verbal and observed behaviours reflecting manifest (direct) themes will be used, supported by an open coding frame (Berg, 2001; Marshall & Rossman, 2011). Closed questionnaire items on baseline coping, decision making, and game enjoyment will be analyzed using descriptive statistics.

INTERVENTION

HOW TO PLAY....'DON'T PUSH YOUR LUCK!'

Game design is evidence-based, developmentally appropriate and uses active learning principles, while reflecting children's vision to create a resource that is colourful and fun.

The key features of the board game include: qualities required for child and family-centred teamwork. Critical thinking steps including reflecting on actions and consequences, and scenarios representing typical life experiences based on quality of life indicators

This Euro game differs from traditional roll and move games; this type of game play emphasizes working through challenges, making decisions, and exploring consequences in a fun manner.

Players explore their everyday life choices, while trying to meet their best interests to be healthy and balanced in 4 key areas:

1. Physical (MY BODY)
2. Emotional (MY FEELINGS)
3. Social (MY FRIENDS & FAMILY)
4. Mental (MY SMARTS)

EXPECTED OUTCOMES

Phase I themes will describe how children and their families evaluate an educational board game; feedback on questionnaire and board game refinement will guide Phase II.

Phase II themes will describe children's and parents' perspectives regarding engagement in decision-making processes for hemophilia self care, and family recommendations for future board game development; descriptive statistics on baseline coping and decision making questionnaires will describe similarities and differences between children's and parent's perspectives; descriptive statistics and open comments on the game enjoyment questionnaire will further identify recommendations for future game development.

We hope to start data collection in fall 2012, and conclude by fall 2013.

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