

## PHOTOGRAPHS OF LIFE: EXPRESSIONS OF SIBLINGS OF CHILDREN WITH DOWN SYNDROME

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**Background:** Considerable evidence suggests that living with a child with Down syndrome can be a source of stress when compared to families raising children who do not have disabilities. This may be because families raising children with Down syndrome not only face similar daily stressors and challenges experienced by families not raising a child with a disability, but also face unique responsibilities and challenges related to the diagnosis of Down syndrome itself. Even though past research has focused on the experiences families have when raising a child with Down syndrome, this research frequently examines parents' perspectives rather than siblings' perspectives. Therefore, it is important to obtain information relative to siblings' perspectives when a family raises a child with Down syndrome, so intervention efforts can be improved and holistic care provided.

**Purpose:** The purposes of this qualitative, descriptive study were to (1) use photography as a method of capturing important symbols in the lives of siblings who have a brother or sister with Down syndrome, (2) identify themes emerging from the photographs taken by these siblings, and (3) use the siblings' narrative interpretations of those photographs to describe the identified themes.

**Methods:** After receiving approval from the institutional review board and after obtaining informed consent from parents and assent from children, seventeen school aged siblings of children with Down syndrome were asked to take photographs of important symbols in their lives within a two week time period. After the snapshots were developed, trained research assistants met individually with each sibling to listen, record, and transcribe the narrative accounts of the photographs. Photographs were analyzed through content analysis using open, axial, and selective coding, and themes and categories identified. Quotes were then selected from the narrative accounts to describe the themes.

**Results:** Analysis revealed two major categories: people/non people. People consisted of family and friends; non people consisted of objects, animals and buildings. Every sibling took at least one photograph of his/her family, and the most frequently photographed family member was the child with Down syndrome. Non people photographs portrayed items of importance to the sibling such as toys, books, electronics, decorations, domestic and non-domestic animals, houses, schools, and churches. Narrative accounts reflected experiences the siblings had with the people/non people in the snapshots and their normal everyday activities.

**Implications:** Communication with children can be facilitated by using photography. In addition, photography provides another way of obtaining information from siblings living with a child with Down syndrome about their life experiences. Finally, information gained not only contributes to our knowledge base, but also allows development of specific intervention plans for siblings of children with Down syndrome.

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