

Every Picture Tells a Story: Effects of Photographic Images on Genetic Counseling and Medical Students' Perceptions of Genetic Conditions

Jennifer R. Holle¹, Patricia McCarthy Veach¹, Ian M. MacFarlane¹, & Bonnie S. LeRoy¹

¹University of Minnesota, Minneapolis, MN

Introduction

Use of Photographic Images in Genetic Medicine

- Used to assist in diagnosis of rare conditions, and patient education about the etiology and prognosis of genetic conditions.
- Currently available sources of photographs are medical textbooks written for healthcare providers.
- Medical textbook photographs capture the individual's vulnerability (Sutton et al., 2006); clinical photos taken while the patient is undressed or unsmiling strips them of their human dignity (Jones, 1996). Clinical photographs do not provide information about patients as people or about their lives.

Positive Exposure

- Non-profit organization dedicated to celebrating genetic differences and promoting human dignity for individuals with genetic conditions by creating photographs that illustrate the *person behind the condition*.
- "currently available medical images illustrating genetic difference are particularly dehumanizing and dispiriting" -www.positiveexposure.org

Previous Research on Photography and Perception

Waxler et al. (2009)	"Being shown photographs in textbooks" was reported by family members to be among the negative aspects of the diagnostic experience (Williams syndrome).
Ahmed et al. (2009)	Both health care providers and mothers of children with Down syndrome believed photographs of children with Down syndrome could bias perceptions of this condition.
Figueiras et al. (1999)	The <i>type</i> of photograph of child with Down syndrome affected expectations of prenatal testing and pregnancy termination
Gething (1992)	Individuals with visible physical impairments (wheelchair users) were rated less socially and psychologically adjusted than when seated in an armchair

To date, no published studies have examined the effects of photographs on health care providers' perceptions of genetic conditions.

Present study

- This study investigated genetic counseling students' and medical students' perceptions of severity, burden, and reproductive options associated with Marfan syndrome and Prader-Willi syndrome

Methods

Recruitment

- 1st and 2nd year genetic counseling students from all ABGC-accredited programs and 1st year UMN medical students
- Email invitation

Photographs

- Clinical images from *Smith's Recognizable Patterns of Human Malformation* and Dr. Robert Gorlin
- Everyday images from *Positive Exposure* - Rick Guidotti, photographer

Online Survey

- Randomized to 1 of 3 tracks: textbook photo, *Positive Exposure* photo, control (no photo); questions completed for both syndromes
- Textual information
- Closed-ended questions regarding severity, QOL, parenting, and reproductive options
- Quality of Life Scale (Short Form-36)
- Impact on Family Scale
- Open-ended questions regarding reaction to photographs

Analyses

- Descriptive statistics
- Multivariate analyses of variance (MANOVAs)
- Qualitative analyses – interpretative content analysis

Photographs



Figure 1. Clinical Photo, Marfan syndrome. From *Smith's*



Figure 2. Everyday Photo, Marfan syndrome. From *Positive Exposure*



Figure 3. Clinical Photo, Prader-Willi syndrome. From Bob Gorlin, MD



Figure 4. Everyday Photo, Prader-Willi syndrome. From *Positive Exposure*

Results

Qualitative Results:

"What was your initial reaction to this photo? How do you think a parent would react to this photo?"

Thematic Differences for Marfan syndrome: Clinical vs. Everyday Emotional Wellbeing:

- Only mentioned in the everyday Marfan photo
"It made me feel that people with Marfan's lived normal, happy lives" –(Med student; Everyday photograph)
- **Comments about photograph: respectful vs. disrespectful**
- Everyday photo: respectful to patient, non-clinical
"Positively. Shows the human side of someone with this disease" – (GC student; everyday photograph)
- Clinical photo: clinical, disrespectful
"Again, it seems a little degrading to the person in the picture. It is important for medical students...to know what the condition looks like, but I think the person in the picture could be painted in a better light" – (Med student; clinical photograph)
- Everyday photo: more severe representation of condition
"This picture was scary because the child looks very different from other children. I think this picture makes the condition seem very severe" – (GC student; everyday photograph)

Phenotype

- Cognitive disability theme in everyday photo
"They would see the disease as extremely scary - that their child would be extremely dysmorphic-looking. Would be "skin-and-bones", have large ears, have strange facial characteristics and may even think that mental retardation is involved (which it's not)" –(GC Student)

Thematic Differences for Prader Willi syndrome: Clinical vs. Everyday Emotional wellbeing

- Everyday photo: Happiness
"He seemed really happy and enjoying life" - (GC Student; everyday photo)
- Clinical Photo: Unhappiness
"This child looks very sad, to the point of depression" -(Med student; clinical photo)

Affective Responses

- Everyday Photo: Positive reactions, pride
- Clinical Photo: fear, anxiety, sadness

Comments about Photograph: respectful vs. disrespectful

- Clinical Photo: disrespectful and dehumanizing
"He's naked! My original reaction reflected my idea of dignity - which I thought was lacking because the patient was posing naked. I suppose this was required in order to show the genital hypoplasia" - (GC Student, clinical photo)
- Everyday Photo: respectful, non-clinical
"I thought it was among the better pictures of individuals with this condition" – (GC Student)

Results (Continued)

Quantitative Results:

- Multivariate analyses revealed significantly higher ratings of QOL for individuals with Prader-Willi syndrome by respondents in the everyday photograph group than by respondents in the clinical photograph group or the "no photo" group, $F(2, 172)=5.64, p=.004$.
- For Prader-Willi syndrome, genetic counseling students endorsed significantly greater effects on parents' reproductive decisions $F(1, 172)=16.44, p<.001$, and significantly less challenging aspects (severity, burden) than did medical students, $F(1, 172)=7.32, p=.008$ than did medical students.

Discussion

Key Findings:

- Content analysis of responses to open-ended items indicate students viewing the everyday photographs perceived them as more respectful to the patient, less medical, and overall more appealing than students viewing the clinical photographs.
- Participants rated the quality of life of individuals with PWS to be significantly higher in the everyday photo group than either other group.
- Genetic counseling students perceived greater differences between groups in parents' reproductive decisions and the challenging aspects of raising a child with PWS than did medical students.

Limitations

- Student sample: Proxies for parents; varied clinical experiences
- Length of survey: Usable response rates: 31%, 34%
- Uneven split in 3 conditions: over representation of Clinical photo group
- Non-standardized photographs: gender; degree of affectedness; respondents' previous exposure to photo or condition
- Self-report does not always equate to actual behavior

Future Research

- Repeat study using parents
- Standardize severity of condition with models
- Study current use of photographs in genetics clinics

Practice Implications

- Do photographs fit with non-directive counseling practices?
- What sources of photographs are appropriate for clinical counseling?

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