

# “If It Helps, It’s Worth a Try”: An Investigation of Perceptions and Attitudes about Genetic Counseling among Southern Manitoba Hutterites

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## INTRODUCTION

- Genetic counseling is defined as, “the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease” [1].
- In order to fulfill this definition, genetic counseling must first reach those in need of the service itself.
- Previous research using the Integrative Model of Behavior Prediction has shown associations between attitudes and intentions to perform health related behaviors and suggests perceived benefits may be a factor underlying beliefs and intention to engage in health related behaviors [2,3].
- To date, only two studies have investigated the general public’s awareness and perceptions of genetic counseling [4,5].
- Little research concerning familiarity with and attitudes and perceptions about genetic counseling has been conducted on founder populations with high prevalence of genetic disease, such as Hutterites. Thus, a population for which these services may provide great benefit has been severely understudied and underrepresented.
- The Hutterites of North America are an Anabaptist religious group grounded in a strong Christian faith. More than 30 autosomal recessive diseases have been reported in Hutterites.

## RESEARCH QUESTIONS

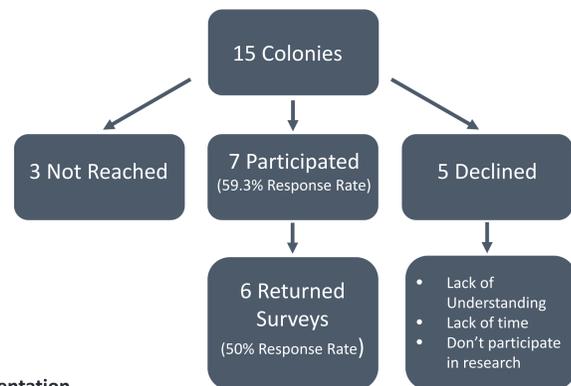
The present investigation, a replication and extension of a previous study [5], assessed self-reported perceptions and attitudes about genetic counseling services among members of southern Manitoba (MB) Hutterite colonies. There were four major research questions:

- How familiar are Hutterites with genetic counseling?
- How accurate are Hutterites’ perceptions about the purpose, scope and practice of genetic counseling?
- What are Hutterites’ attitudes about genetic counseling services?
- Would Hutterites be willing to use genetic counseling services?

## METHODS

### Study Participants and Procedures

- Contacted Hutterite Colony ministers and managers in southern Manitoba by phone. Recruitment was based on personal connections to certain Hutterite colonies, proximity to hometown of Morris, Manitoba, and suggestions from previously visited colonies.
- Arrangements were made to visit the colony and invite members to participate in an anonymous survey.
- A total of 111 individuals from southern Manitoba Hutterite Colonies completed the survey.



### Instrumentation

- A questionnaire designed by Riesgraf et al. (2015) was modified for use in this study to assess the major research questions.
- The modified survey was piloted with a geneticist and genetic counselor familiar with Manitoba Hutterite culture.

### Data Analyses

- Logistic regression analysis was done to determine which variables were significant predictors of willingness to use genetic counseling services. This model had an AIC of 100.75 and Nagelkerke’s R<sup>2</sup> = 0.37.
- Responses to an open-ended question asking respondents to explain why they would or would not use genetic counseling services were analyzed using an interpretive content analysis method.

## RESULTS

Table 1 Respondent Demographics and Awareness of Genetic Counseling (N=111).

Variable	Number	Percent	Variable	Number	Percent
<b>Gender</b>			<b>Heard the Term GC</b>		
Female	64	42.3	Yes	55	49.5
Male	47	57.7	No	41	36.9
<b>Race</b>			Not sure	15	13.5
Caucasian	104	93.7	<b>How Heard of GC</b>		
Other <sup>a</sup>	7	6.3	Family Friend	36	32.4
<b>Children</b>			Media	18	16.2
Yes	66	59.5	A class	13	11.7
No	45	40.5	Received Services	12	10.8
<b>Education</b>			Other <sup>b</sup>	9	8.1
Less than High School	52	46.8			
High School	38	34.2			
Some College	3	2.7			
Post -Bach	18	16.2			

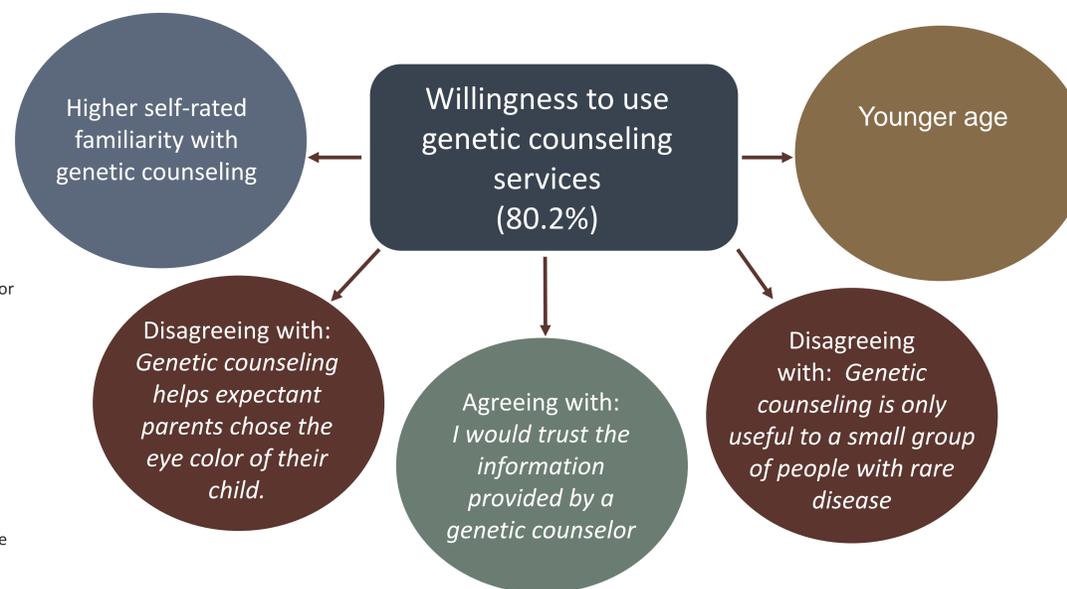
Note. <sup>a</sup>Other: Hutterite(5); Canadian Hutterite(2) <sup>b</sup>Other: University course; Had it myself; University of Manitoba; Doctor(n=4); Minister/teacher.

Table 2 Means, Standard Deviations and Medians for Responses to Statements about Genetic Counseling (N=111) compared to Riesgraf et al. (2015).

Statement	M <sup>a</sup>	SD	Mdn	M <sup>b</sup>	SD <sup>c</sup>	Mdn <sup>d</sup>
<b>Purpose, scope, and practice of genetic counseling</b>						
Genetic counseling is confidential <sup>a</sup>	3.48	0.90	4.00	3.64	0.69	4.00
Genetic counselors must receive a lot of special training to do their job <sup>b</sup>	3.47	0.96	4.00	3.59	0.61	4.00
Genetic counselors give people emotional support <sup>a</sup>	3.38	0.82	4.00	3.25	0.84	3.00
The goal of genetic counseling is to keep genetic problems out of society	2.99	1.14	3.00	2.29	1.05	2.00
Genetic counselors require people to have genetic tests	2.93	1.21	3.00	2.57	1.05	3.00
Genetic counseling may be useful to someone with cancer in their family <sup>a</sup>	2.85	1.18	3.00	3.46	0.69	4.00
Genetic counseling can help cure a genetic problem	2.28	1.24	2.00	2.37	1.07	2.00
Genetic counseling is only useful to a small group of people with rare diseases	1.53	0.88	1.00	1.72	0.86	1.23
Genetic counselors advise women to get abortions when there is a problem	1.41	0.83	1.00	1.59	0.83	1.00
Genetic counseling helps expecting parents choose the gender of their child	1.23	0.69	1.00	1.54	0.86	1.00
Seeing a genetic counselor could cause someone to lose their job	1.21	0.69	1.00	1.56	0.83	1.00
Genetic counseling is a service mainly for pregnant women	1.20	0.42	1.00	1.73	0.86	1.00
Genetic counseling helps expecting parents choose the eye color of their child	1.09	0.37	1.00	1.41	0.79	1.00
<b>Attitudes about genetic counseling</b>						
I would trust the information provided by a genetic counselor	3.49	0.69	4.00	3.19	0.66	3.00
Genetic counseling is in line with my values	3.42	0.82	4.00	2.88	0.82	3.00

Note. <sup>a</sup> Item reflects an accurate perception of genetic counseling; <sup>b</sup> Scale: 1 = Disagree, 2 = Somewhat Disagree, 3 = Somewhat Agree, 4 = Agree; <sup>c</sup> Data from Riesgraf et al (2015).

Figure 1 Results of Logistic Regression Analysis Modeling of Willingness to Use Genetic Counseling Services (N=111).



## RESULTS

Table 3 Themes, Categories and Examples of Responses Regarding Willingness to Use Genetic Counseling Services.

Theme & Category	n <sup>a</sup>	Illustrative example
<b>Would use genetic counseling services</b>		
Family or personal risk/diagnosis	31	
Hypothetical risk/diagnosis	24	<ul style="list-style-type: none"> <li>I would find out if I had a disease that runs in my family, or if I'm a carrier or not.</li> <li>If a child has a genetic illness.</li> <li>I would like to [have] counselling since muscular dystrophy runs in my family. So see if I can learn more on the matter.</li> </ul>
Current genetic health concerns in family	7	
Family Planning	15	
Preconception/prenatal planning	10	<ul style="list-style-type: none"> <li>I would use genetic counselling when thinking about or deciding whether to begin a family of my own, so that I would be aware of possible risks with doing so.</li> <li>To see what the risk is before getting married.</li> </ul>
Marriage planning	5	
Education	14	<ul style="list-style-type: none"> <li>To learn more about the disorders that we face.</li> </ul>
Cultural Risk/Diagnosis	7	<ul style="list-style-type: none"> <li>Given the shallow genetic pool among Hutterites in North America, genetic conditions are a reality that we need to take seriously. Genetic Counselling is one service that can help negotiate this reality.</li> </ul>
Pragmatism	5	<ul style="list-style-type: none"> <li>If it can help my children why wouldn't I?</li> </ul>
Health Management	4	<ul style="list-style-type: none"> <li>To find out if any of my children have a particular disease one that would generally show up later, to better prepare the child and do any required therapy to starve [sic] off the effects as long as possible.</li> </ul>
Support	4	<ul style="list-style-type: none"> <li>There are specific diseases in specific genealogies and I believe people should not need to navigate these situations alone. GC's may be a way for those families to find support and to give them the language to communicate their needs/fears, concerns.</li> </ul>
Important/useful- No supporting information	3	<ul style="list-style-type: none"> <li>I think genetic counselling is important.</li> </ul>
Miscellaneous	1	<ul style="list-style-type: none"> <li>My mother was one of the last midwives among us: she was strikingly well-red [sic] and in retrospect I realize that the conversations I had heard her having with other Hutterite women all my life constituted genetic counselling in many ways and women came to her for that. She was an incredible asset to our Hutterite Community.</li> </ul>
<b>Would not use genetic counseling services</b>		
No perceived need	2	<ul style="list-style-type: none"> <li>No need.</li> </ul>
Religious beliefs	2	<ul style="list-style-type: none"> <li>Because you should relay [sic] on God.</li> </ul>
Lack of information	1	<ul style="list-style-type: none"> <li>Don't know enough about it.</li> </ul>
Miscellaneous	4	<ul style="list-style-type: none"> <li>Common sense.</li> </ul>

## CONCLUSIONS & FUTURE DIRECTIONS

### Familiarity with Genetic Counseling

- About half of the sample reported having heard the term genetic counseling prior to completing the survey.
- Greater familiarity among Canadian Hutterites compared to sample of Canadian general public [4].

### Perception of Purpose, Scope and Practice

- Accurate perceptions of scope and practice with variability in perceptions of the role of genetic testing and the goal of genetic counseling.

### Attitudes about Genetic Counseling

- Overall favorable attitude. More favorable attitude and more in line with their values than Riesgraf et al. [5].

### Willingness to Use Genetic Counseling Services

- Over 80% of the sample indicated there were circumstances in which they would use genetic counseling services compared to about half of Riesgraf et al.'s sample.

### Partially replicates and extends Riesgraf et al.'s (2015) findings

- Hutterites demonstrated unique factors that appear to be culturally based.

### Study Limitations

- Convenience sampling (subgroup Schmiedeleut, progressive colonies).
- Hypothetical willingness to use genetic counseling services may not generalize to actual willingness or uptake.

### Practice Implications

- Suggests potential benefit of developing educational initiatives aimed at raising awareness and understanding of genetic counseling services.
- Hutterite culture itself plays a role in willingness to use genetic counseling services.

### Research Recommendations

- Qualitative interviews.
- Comparative studies involving Hutterites from the U.S. and extension to other Hutterite subgroups.
- Other cultural groups.

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