Expectations of the parenting experience and willingness to consider selective termination for Down Syndrome

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Abstract This study examines the dominant normative perceptions of parenting a child with Down Syndrome, and the relationship of these perceptions to willingness to consider selective termination subsequent to a foetal diagnosis of Down Syndrome. Within a community sample (N=355), the perceptions of parenting a child with Down Syndrome were less positive than those of parenting either a child with muscular dystrophy or a child with no disability, especially in terms of the anticipated rewards (personal enrichment and family continuity) associated with the parenting experience. Further, the expectation of less personal enrichment as a result of parenting a child with Down Syndrome emerged as a significant predictor of willingness to abort a diagnosed foetus, although the expectation of enhanced parental costs did not, suggesting that it is the perception of fewer rewards associated with parenting a child with Down Syndrome that are salient in decisions regarding selective abortion. The role of negative stereotypes and implications for interventions are discussed.

Prenatal diagnostic testing (PDT; e.g. amniocentesis, chorionic villus sampling) offers expectant parents the potential for more control over the birth of a disabled child by providing relevant information about the genetic and health status of a foetus during pregnancy. However, there are no therapeutic interventions available for most conditions which testing detects. Consequently, the options available to prospective parents following a diagnosis of foetal disease or disability are to either prepare for a life parenting a child with special needs, or to terminate the pregnancy (Rothenberg & Thomson, 1994; Schwartz-Cowan, 1994).

Most individuals responding to community surveys, when asked in the hypothetical, indicate that they would not abort a pregnancy following a PDT diagnosis of disability or disease (Evers-Kiebooms et al., 1993; Green et al., 1993; Singer, 1993). However, clinical uptake rates indicate that a large number of individuals who actually receive a diagnosis of foetal disease or disability do decide to end the pregnancy on the basis of this information (Rapp, 1988; Edwards et al., 1989; Palomaki et al., 1996). One
possible reason for this discrepancy is that hypothetical situations do not provide us with many of the cues and factors that guide decisions in real life. When expectant parents are confronted with a diagnosis of foetal abnormality, the reality of the situation and the personal implications of raising a child with a disability may become salient. It is likely that individuals faced with this situation actively create scenarios of their possible parenting future, and this personalization of the process may tend to sway them towards selective abortion (Huys et al., 1992).

Willingness to consider selective abortion appears to vary depending on the disease or disability diagnosed via PDT (Wertz et al., 1991). A recent study concluded that, although individuals faced with a hypothetical scenario indicated a general intention not to abort a foetus following a diagnosis of spina bifida and hemophilia, they were slightly more uncertain of their decision following a diagnosis of Down Syndrome (Bell & Stoneman, 2000). This uncertainty, or potential willingness to consider the selective abortion of a foetus diagnosed with Down Syndrome, is reflected in the rates of actual termination. The termination rates for Down Syndrome following a prenatal diagnosis far exceed the termination rates for other disabilities (Rapp, 1988; Green et al., 1993). A recent review of the literature concluded that, across 20 published studies, the termination rate following a prenatal diagnosis of Down Syndrome averaged 92% (Mansfield et al., 1999). In comparison, the average termination rates for spina bifida and Turner Syndrome were 64% and 72%, respectively, while Klinefelter Syndrome evidenced the lowest termination rate at 58%. What is it about the prospect of giving birth to a child with Down Syndrome that sways parents toward termination?

The assumptions underlying selective abortion appear to be that disability can reduce quality of life to an extent that non-existence is preferable to living with a disability (Kaplan, 1994) and/or that the burdens of parenting a disabled child outweigh the joys (Milner, 1993). There is preliminary evidence that decisions regarding PDT use and subsequent termination following a diagnosis of disability are influenced by prejudicial attitudes toward persons with disabilities (Bell & Stoneman, 2000), the perceived enhanced costs and lack of rewards associated with parenting a child with a disability (Meryash, 1992; Lawson, 2001), and the perceived inability to cope with raising a child with a disability (Evers-Keibooms et al., 1993). Applying these findings to the specific case of Down Syndrome, the divergent selective abortion rates across conditions may be due in part to a perception that Down Syndrome is a more serious condition, in terms of its impact on both quality of life and the parenting experience. In fact, past researchers have posited that the higher rates of termination following a diagnosis of foetal Down Syndrome likely reflect a more negative attitude toward parenting a child with cognitive impairment (Faden et al., 1987; Mansfield et al., 1999).

A vital gap in the literature is an examination of what constitutes the attitudes toward parenting a child with Down Syndrome, how these differ from the attitudes toward parenting children with other disabilities and how these attitudes relate to the willingness to terminate a pregnancy subsequent to a diagnosis. Although past researchers have concluded that decisions to terminate following a diagnosis are influenced by the perceived increased costs or lack of rewards associated with parenting a child with a disability (Meryash, 1992; Lawson, 2001), there are two main limitations to this research. The first involves the global measurement of costs and rewards. Measuring the anticipated costs and rewards as global constructs does not allow differences in specific aspects of parenting to be revealed. It would be more informative
to decipher which dimensions of parenting are perceived to be most influenced if the child has Down Syndrome.

The perception of the parenting experience (either anticipated or experienced) is multidimensional in nature. Qualitative interviews and surveys with thousands of individuals across numerous countries (both industrialized and developing nations) and cultures lead to the consensus that parenting is a complex construct with many interrelated dimensions (Hoffman & Hoffman, 1973; Arnold et al., 1975). By employing a multidimensional measure of the costs and rewards associated with parenting, the present studies will more clearly delineate how a diagnosis of Down Syndrome may influence the expectations of the parenting experience.

The second main limitation of past studies is that they have either defined disability as a broad category (Lawson, 2001), or have focused on the global parental costs/rewards within one identified disability category (Meryash, 1992). In order to determine if more negative attitudes toward parenting a child with Down Syndrome underlie the discrepant termination rates, there needs to be an investigation of whether the attitudes toward parenting a child with Down Syndrome are more negative than are the attitudes toward parenting either children with differing disabilities, or children with no disability.

The present study undertakes to address these issues by examining whether the dominant perceptions of parenting differ depending on the disability of the child, and if so, what aspects of parenting are most influenced. Specifically, the perceptions of parenting a child with Down Syndrome will be compared with both the perceptions of parenting a child with a physical disability (muscular dystrophy) and the perceptions of parenting a child with no disability. The extent to which these expectations of parenting predict decisions to terminate the pregnancy following a diagnosis will also be examined by comparing the predictors of willingness to abort for foetal Down Syndrome with those factors which predict willingness to abort following a diagnosis of a physical disability (muscular dystrophy) in order to identify discrepancies.

Based upon the differences observed in termination rates following prenatal testing, it is hypothesized that the perceptions of parenting a child with Down Syndrome will be less positive on all dimensions of the parenting experience than those of parenting a child with muscular dystrophy, which in turn will be less positive than the expectations of parenting a non-disabled child. It is further hypothesized that the largest differences in parenting expectations between the target categories will be observed in relation to parenting rewards (i.e. enrichment and continuity), as past research has suggested that parenting a child with a disability is associated more with a relative absence of anticipated rewards rather than enhanced parenting costs (Lawson, 2001).

Finally, it is expected that the perceptions of parenting a child with Down Syndrome will predict willingness to selectively terminate following a diagnosis of Down Syndrome. Likewise, it is expected that the perceptions of parenting a child with muscular dystrophy will predict willingness to selectively terminate following a diagnosis of muscular dystrophy. It is further predicted that lack of associated parenting rewards will account for more unique variance in willingness to consider selective termination for both conditions than will associated parenting costs. Finally, anticipated parental rewards are expected to be more influential in predicting willingness to terminate for Down Syndrome than muscular dystrophy.
Method

Participants and procedure

The potential participant pool contained 3,125 individuals from all employee categories present at a mid-Western Canadian university campus and thus represented a wide range of diversity on demographic variables. A survey package including a questionnaire, a cover letter introducing the research project and a postage paid return envelope was mailed to a random sample of 600 university employees from the larger pool.

Participants were randomly assigned to receive one of three versions of a questionnaire that asked them to imagine that they had just become the parent of a child, and to respond to the questionnaire in reference to this hypothetical child. Although all response items were identical across the questionnaires, the three versions differed with respect to the disability status of the target child. Version 1 instructed participants to complete the questionnaire with respect to parenting a child with Down Syndrome; Version 2 instructed participants to respond with respect to parenting a child with muscular dystrophy; and Version 3 instructed participants to answer with respect to parenting a child without a disease or disability.

A brief vignette that described the target child accompanied each version of the questionnaire. These vignettes were included to ensure that those participants who were not familiar with the disability conditions would be provided some basic information on which to base their responses. The vignette provided a brief description of the expected developmental trajectory of the child, and was presented as if the information had been supplied by a physician shortly after the birth of the target child. The information provided was intentionally very brief in order to maximize the likelihood of tapping into dominant stereotypes regarding the target conditions. The exact vignettes for the three conditions are as follows:

No disability vignette:

‘Please imagine that you have just become the parent of a child. Your physician has told you that your child is very healthy. Specifically the physician informs you that your child is expected to develop normally and will achieve the same developmental milestones (e.g. walking, talking) and intellectual abilities as other children of the same age.’

Down Syndrome vignette:

‘Please imagine that you have just become the parent of a child with Down Syndrome, a chromosomal abnormality which results in mental retardation. Your physician has told you that because Down Syndrome is associated with a range of developmental difficulties your child will likely not achieve the same developmental milestones as other children of the same age. Specifically, the physician informs you that your child will likely not sit, crawl or walk as soon as other children, and will also show a deficit in cognitive skills such as talking and memory ability. Your physician also notes that, although your child will not achieve intellectually like other children of the same age, with the proper supports your child may be able to go to school with other children from the community.’

1 Information taken from the Down Syndrome Information Network website: http://www.down-syndrome.info/topics/keyfacts.htm
Muscular dystrophy vignette:

‘Please imagine that you have just become the parent of a child with muscular dystrophy, a genetic disorder that affects the muscles of the body. Your physician has told you that your child will gradually lose muscle use and thus be unable to control body movement. Specifically, the physician informs you that eventually the muscle weakness will make walking very difficult and a wheelchair will likely be necessary. Your physician also notes that this disease does not affect your child’s intelligence, and although your child may have difficulty speaking, with the proper supports your child will likely be able to go to school with other children from the community.\(^2\)

The information provided in the Down Syndrome and muscular dystrophy vignettes represented a moderate degree of severity of the target condition. A moderate degree of severity was chosen over mild expression due to the past findings that medical professionals either focus on the severity and burdens associated with Down Syndrome (Milner, 1993) or do not provide descriptions of the likely expression of genetic disorders (Marteau et al., 1993). When the task of defining the outcomes of Down Syndrome is left to imagination, people tend to draw on negative stereotypes and construct an image of severe disability (Lawson, 2001). Thus a depiction of moderate severity of disability was deemed appropriate as it would approximate the lower level of severity that most individuals in the prenatal testing situation would conjure in making decisions about the pregnancy.

Reminder cards were mailed 1 week after the initial mail-out in correspondence with Dillman’s method for increasing response rates in mail surveys (Dillman, 2000). In total 355 completed surveys were returned and 19 surveys were returned undeliverable due to the target respondent no longer being at the available address, resulting in a response rate of 61.1%. The response rate is in keeping with most survey studies and is considered acceptable (Krosnick, 1999). The data were screened in order to ensure that none of the respondents were parents of a child with mental retardation or a serious physical disability. This was necessary as the purpose of the present study was to examine stereotypes regarding parenting a child with a disability rather than actual experience. In total, 123 Version 1 (child with Down Syndrome), 133 Version 2 (non-disabled child) and 99 Version 3 (child with muscular dystrophy) surveys were included in the final sample. Table 1 presents a summary of the sample demographic characteristics by group membership. As indicated in Table 1, the three target groups did not significantly differ with respect to salient demographic characteristics.

**Measures**

*Perceptions of Parenting Inventory (POPI).* The POPI is a 28-item measure that taps into the multidimensional construct of the perceptions of parenting (Lawson, 2004). It provides both an overall index of the perceptions of parenting and sub-scales which measure the salient ways in which parenting impacts an individual’s life. Taken together the POPI sub-scales measure: personal enrichment (eight items targeting the parent’s happiness, pride, fun, personally rewarding, enjoyment in watching the child grow, rewards to family, growing closer to spouse and becoming a better person as a result of

\(^2\) Information taken from the Muscular Dystrophy Canada website: http://www.muscle.ca
the parenting experience), continuity of self and family (four items targeting anticipating being a grandparent, continuation of family line, adult relationship with child and anticipating the child would be of assistance as parent grows elderly), social isolation (four items targeting interference with the parent’s important social relationships and leisure activities), commitment (four items targeting immediate and long-term care responsibilities of parenting) and tangible instrumental costs (five items encompassing financial expense, emotional and physical toll). It also contains a sub-scale measuring the perceived support available for parenting efforts (three items targeting support from family, friends and community), reflecting the importance of the social context in which reproductive decisions are made. The POPI has evidenced sound factor structure, adequate internal reliabilities and construct validity (Lawson, 2004). The POPI appears to be a reliable and valid tool for measuring the perceptions of parenting, regardless of whether these perceptions are based on expectations or experience.

Because the POPI was developed for measuring the perceptions of parenting in general, the coefficient alphas for the POPI sub-scales were calculated within the present study to examine the internal reliabilities associated with using the POPI for target children distinguished by their disability status. The resulting coefficient alphas indicate that the POPI demonstrates sufficient reliability in relation to measuring the perception of parenting the three target groups: non-disabled children (coefficient alphas range from 0.85 to 0.64); children with Down Syndrome (coefficient alphas range from 0.90 to 0.65); and children with muscular dystrophy (coefficient alphas range from 0.87 to 0.70).

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Down Syndrome</th>
<th>Muscular dystrophy</th>
<th>No disability</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, M (SD; range)</td>
<td>41.6 (10.1; 18–62)</td>
<td>44.1 (9.6; 22–65)</td>
<td>41.7 (10.4; 22–65)</td>
<td>0.134</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>46 (37.3%)</td>
<td>35 (35.7%)</td>
<td>54 (40.6%)</td>
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</tr>
<tr>
<td>Female</td>
<td>76 (62.3%)</td>
<td>63 (64.3%)</td>
<td>79 (59.4%)</td>
<td>0.743</td>
</tr>
<tr>
<td>Education (highest level)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>32 (26.0%)</td>
<td>21 (21.4%)</td>
<td>34 (25.6%)</td>
<td></td>
</tr>
<tr>
<td>College/technical</td>
<td>22 (17.9%)</td>
<td>20 (20.4%)</td>
<td>16 (12.0%)</td>
<td></td>
</tr>
<tr>
<td>Undergraduate degree</td>
<td>32 (26.0%)</td>
<td>22 (22.4%)</td>
<td>38 (28.6%)</td>
<td></td>
</tr>
<tr>
<td>Graduate degree</td>
<td>37 (30.1%)</td>
<td>35 (35.7%)</td>
<td>45 (33.8%)</td>
<td>0.595</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>17 (13.9%)</td>
<td>17 (17.5%)</td>
<td>23 (17.3%)</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>94 (77.0%)</td>
<td>73 (75.3%)</td>
<td>99 (74.4%)</td>
<td></td>
</tr>
<tr>
<td>Divorced/widowed</td>
<td>11 (9.0%)</td>
<td>7 (8.2%)</td>
<td>11 (8.3%)</td>
<td>0.930</td>
</tr>
<tr>
<td>Parenting status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have children</td>
<td>92 (74.8%)</td>
<td>76 (78.4%)</td>
<td>90 (67.7%)</td>
<td></td>
</tr>
<tr>
<td>Childless</td>
<td>31 (25.2%)</td>
<td>21 (21.6%)</td>
<td>43 (32.3%)</td>
<td>0.171</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>103 (85.1%)</td>
<td>84 (85.7%)</td>
<td>117 (88.0%)</td>
<td></td>
</tr>
<tr>
<td>First Nation</td>
<td>5 (4.1%)</td>
<td>4 (4.1%)</td>
<td>4 (3.0%)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>6 (5.0%)</td>
<td>5 (5.1%)</td>
<td>9 (6.8%)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>7 (5.8%)</td>
<td>5 (5.1%)</td>
<td>3 (2.3%)</td>
<td>0.826</td>
</tr>
</tbody>
</table>

Note. Not all respondents supplied demographic information, therefore percentages are based on the total of those completing each demographic item.
Respondents to the POPI are instructed to think about what parenting the target child would be like, and to rate the extent to which they perceive that each of 28 aspects of parenting would be personally experienced in parenting the target child. All items are scored from strongly disagree to strongly agree on 7-point Likert scales, with higher scores reflecting stronger agreement that the concept encompassed by the item would be part of the parenting experience. The overall index is comprised by reverse scoring negative items and totalling responses resulting in a potential response range of 28 to 196, with higher scores indicating a more positive perception of the parenting experience. Sub-scale scores are formed by computing the mean response to the items encompassed by the sub-scale, and thus range from 1 to 7, with higher scores reflecting a greater endorsement that the dimension being measured would be personally experienced in the parenting situation.

The Scale of Attitudes Toward Disabled Persons. The Scale of Attitudes Toward Disabled Persons (SADP; Antonak & Livneh, 1988) is a 24-item self-administered instrument that measures general attitudes toward disabled persons as a group. Antonak and Livneh report that the SADP evidences satisfactory reliability and validity for measuring this construct. Respondents are asked to respond to each statement using a 6-point scale, ranging from $-3$ (‘I disagree very much’) to +3 (‘I agree very much’). An index of global attitude toward persons with disabilities is computed by weighting and summing item responses so that higher scores indicate a more favourable attitude.

Personal information. Participants were also asked to indicate the strength of their religious beliefs (on a 5-point scale ranging from ‘not at all strong’ to ‘extremely strong’) and the likelihood that they would terminate a pregnancy subsequent to a prenatal testing diagnosis for the target condition to which they had been assigned (on a 5-point scale ranging from ‘definitely not’ to ‘definitely’). They were also asked to indicate their level of personal familiarity with someone with: (a) Down Syndrome or other forms of mental retardation and (b) muscular dystrophy or other forms of serious physical disability on a 3-point scale [1=‘I have never known anyone with mental retardation/serious physical disability’; 2=‘I have/had some familiarity with someone with mental retardation/serious physical disability but not a close relationship (e.g. neighbour, church member; distant relation, person in workplace)’; 3=‘I have/had a close relationship with someone with mental retardation/serious physical disability (e.g. immediate family member, close friend)’]. Participants also supplied demographic information such age, education, marital status, ethnicity, sex, and number of current children.3

3 Compared to the general population, the present sample contains an over-representation of highly educated individuals. As it is possible that highly educated individuals might differ from those with less education in their attitudes towards specific disabilities, especially those involving intellectual deficits and their perceptions of parenting a child with such disabilities, the mean responses on the main research variables (SADP, POPI sub-scales, and likelihood of selective abortion) were compared across educational level categories (high school, college/technical, university undergraduate degree, graduate degree) within each disability group using one-way analysis of variance. Within the Down Syndrome group there were no significant differences across the educational levels for any of the variables. Within the muscular dystrophy group, there was only one significant difference found. Specifically education level was found to be related to
Results

Preliminary analyses examined base rates of familiarity with the target disabilities, and group differences in attitude towards persons with disabilities (as measured by SADP) and willingness to consider selective termination. A large number of respondents indicated that they had no personal familiarity with someone with either mental retardation (61.4%) or serious physical disability (49.3%). No significant difference in likelihood of termination subsequent to a hypothetical foetal diagnosis was found between the conditions of Down Syndrome (M=2.79) and muscular dystrophy (M=2.81), t(220)=0.132; p=0.895. However, differences in SADP scores were evident, F(2, 352)=5.7, p=0.004, with the respondents to the Down Syndrome version (M=103.6) reporting significantly lower ratings than either the respondents to the muscular dystrophy (M=109.8) or the non-disabled (M=111.1) versions, which did not differ significantly.

A significant difference in the global POPI scores across questionnaire versions was detected via one-way analysis of variance, F(2, 352)=79.8, p<0.001. Post-hoc comparison revealed that the global perceptions of parenting a child with Down Syndrome (M=101.5) was significantly less positive than that of parenting a non-disabled child (M=132.1), p<0.001 and marginally less than that of parenting a child with muscular dystrophy (M=106.7), p=0.062. The global perceptions of parenting a child with muscular dystrophy were also significantly less positive that those of parenting a non-disabled child, p<0.001.

A multivariate analysis of variance revealed that the POPI sub-scale scores, as a combined dependent variable, also differed across the three questionnaire versions, F(12, 696)=15.8, p<0.001. The subsequent univariate analyses were then examined to test for group differences in each of the individual POPI sub-scale scores. Significant differences were found on all sub-scales: enrichment, F(2, 352)=69.4, p<0.001; instrumental costs, F(2, 352)=34.9, p<0.001; commitment, F(2, 352)=18.6, p<0.001; social isolation, F(2, 352)=15.2, p<0.001; family continuity, F(2, 352)=83.1, p<0.001; and perceived social support, F(2, 352)=6.85, p=0.001.

Follow-up post-hoc comparisons were conducted in order to interpret these significant group differences. See Table 2 for a summary of these analyses. These tests revealed that the perception of parenting a child with Down Syndrome or muscular dystrophy was less positive than that of parenting a child with no disability on all sub-scale dimensions. Further, significant differences were also evident between the Down Syndrome and muscular dystrophy groups, with mean scores on the enrichment and family continuity sub-scales being lower for those who completed the questionnaire in relation to parenting a child with Down Syndrome. Supporting the hypothesis, the effect sizes reveal that the disability status of the child had the largest influence on the sub-scales of enrichment and family continuity, which measure anticipated parental rewards.

As a preliminary step before conducting regression analyses, the zero-order correlations were calculated between potential predictor variables and the criterion SADP scores, F(3, 94)=3.93, p=0.001. Individuals with college/technical level education evidenced significantly less positive attitudes towards persons with disabilities (M=103.4) than any of the other three educational levels which did not differ from each other (high school M=109.4, undergraduate M=111.5, graduate M=117.5), p=0.007. Based on these results, education level is not related to the perceptions of parenting either a child with Down Syndrome or muscular dystrophy and as such is not exerting a biasing influence on the study.
variable (likelihood of selective abortion) within each target disability response group in order to restrict the regression analysis to only those predictors which evidenced a significant correlation with the criterion, and to detect any possible multicollinearity (correlations above 0.70) amongst predictor variables. The results of these correlational analyses are presented in Table 3. With respect to the Down Syndrome group, familiarity with persons with Down Syndrome and the perceived instrumental costs and commitment associated with parenting a child with Down Syndrome did not significantly correlate with likelihood of aborting a foetus diagnosed with Down Syndrome, and thus were excluded from the subsequent regression analysis. In addition, the inter-correlations between instrumental costs and both commitment and isolation suggested potential multicollinearity, further supporting the exclusion of the POPI sub-scales of instrumental costs and commitment.

With respect to the muscular dystrophy group, familiarity with persons with muscular dystrophy and the perceived commitment associated with parenting a child with Down Syndrome did not significantly correlate with likelihood of aborting a foetus diagnosed with Down Syndrome, and thus were excluded from the subsequent regression analysis. In addition the high correlation between isolation and instrumental costs was suggestive of potential multicollinearity supporting the removal of instrumental costs from the regression equation. Thus, the resulting set of predictor variables was the same for each subsequent regression analysis, and encompassed attitudinal characteristics (strength of religious beliefs and SADP scores) and specific perceptions of parenting a child with the target disability (POPI sub-scales of enrichment, isolation, continuity of self and family and perceived social support).

Table 4 presents the results of the hierarchical regression conducted on the sub-sample of respondents who completed the Down Syndrome version of the questionnaire in which the predictor variables were regressed on personal likelihood of aborting a foetus diagnosed with Down Syndrome. The scores on the enrichment and family continuity sub-scales were entered on the final step in order to provide the strongest test of the hypothesis that anticipated parenting rewards uniquely contribute to the willingness to consider selective termination. After the third step, with all the variables in the equation, $R=0.68$, $F(6,115)=16.65$, $p<0.001$. Following the introduction of the personal factors (strength of religious beliefs and SADP scores) $R$ was significantly different from zero, $R^2=0.314$, $F(2,119)=27.22$, $p<0.001$. The addition of scores on the POPI sub-scales of perceived social support and isolation on

<table>
<thead>
<tr>
<th>POPI Scale</th>
<th>Down Syndrome</th>
<th>Muscular dystrophy</th>
<th>No disability</th>
<th>$p$</th>
<th>Eta²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enrichment</td>
<td>4.9a (1.2)</td>
<td>5.1b (1.0)</td>
<td>6.2c (0.66)</td>
<td>&lt;0.001</td>
<td>0.283</td>
</tr>
<tr>
<td>Isolation</td>
<td>4.7a (1.3)</td>
<td>4.5b (1.2)</td>
<td>3.8b (1.5)</td>
<td>&lt;0.001</td>
<td>0.080</td>
</tr>
<tr>
<td>Commitment</td>
<td>5.5a (1.3)</td>
<td>5.4a (1.2)</td>
<td>4.6b (1.3)</td>
<td>&lt;0.001</td>
<td>0.096</td>
</tr>
<tr>
<td>Instrumental costs</td>
<td>5.6a (1.0)</td>
<td>5.6a (0.95)</td>
<td>4.7b (1.1)</td>
<td>&lt;0.001</td>
<td>0.165</td>
</tr>
<tr>
<td>Continuity</td>
<td>3.1a (1.1)</td>
<td>3.6a (1.3)</td>
<td>4.8c (0.78)</td>
<td>&lt;0.001</td>
<td>0.321</td>
</tr>
<tr>
<td>Perceived support</td>
<td>4.7a (1.2)</td>
<td>5.0a (1.2)</td>
<td>5.3b (1.1)</td>
<td>&lt;0.001</td>
<td>0.037</td>
</tr>
</tbody>
</table>

Note. Possible scores range 1–7 with higher scores indicating a greater perception that the aspect is associated with parenting. Standard deviations are listed in parentheses.

**abc** Differing subscripts across each row indicate mean scores that differ significantly at $p<0.05$. 

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**Table 2. Perceptions of parenting across disability status groups.**
Table 3. Inter correlations between regression variables within target disability groups.

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Religiosity</td>
<td>–</td>
<td>0.052</td>
<td>0.141</td>
<td>0.375*</td>
<td>-0.142</td>
<td>-0.185*</td>
<td>-0.159</td>
<td>0.236*</td>
<td>0.175</td>
<td>-0.382*</td>
</tr>
<tr>
<td>2. SADP</td>
<td>-0.011</td>
<td>–</td>
<td>0.055</td>
<td>0.346*</td>
<td>-0.263*</td>
<td>-0.269*</td>
<td>-0.389*</td>
<td>0.210*</td>
<td>0.225*</td>
<td>-0.429*</td>
</tr>
<tr>
<td>3. Familiarity</td>
<td>0.012</td>
<td>-0.054</td>
<td>–</td>
<td>0.121</td>
<td>-0.149</td>
<td>-0.026</td>
<td>-0.100</td>
<td>-0.069</td>
<td>0.118</td>
<td>-0.106</td>
</tr>
<tr>
<td>4. Enrichment</td>
<td>0.181</td>
<td>0.382*</td>
<td>-0.029</td>
<td>–</td>
<td>-0.287*</td>
<td>-0.226*</td>
<td>-0.337*</td>
<td>0.441*</td>
<td>0.447*</td>
<td>-0.585*</td>
</tr>
<tr>
<td>5. Inst. costs</td>
<td>-0.140</td>
<td>-0.195</td>
<td>0.028</td>
<td>-0.465*</td>
<td>–</td>
<td>0.705*</td>
<td>0.673*</td>
<td>-0.253*</td>
<td>-0.032</td>
<td>0.152</td>
</tr>
<tr>
<td>6. Commitment</td>
<td>0.030</td>
<td>-0.371*</td>
<td>-0.052</td>
<td>-0.221*</td>
<td>0.474*</td>
<td>–</td>
<td>0.529*</td>
<td>-0.285*</td>
<td>0.079</td>
<td>0.107</td>
</tr>
<tr>
<td>7. Isolation</td>
<td>-0.163</td>
<td>-0.237*</td>
<td>0.045</td>
<td>-0.464*</td>
<td>0.641*</td>
<td>0.356*</td>
<td>–</td>
<td>-0.341*</td>
<td>-0.067</td>
<td>0.278*</td>
</tr>
<tr>
<td>8. Continuity</td>
<td>0.040</td>
<td>0.182</td>
<td>0.027</td>
<td>0.539*</td>
<td>-0.358*</td>
<td>-0.132</td>
<td>-0.262*</td>
<td>–</td>
<td>0.092</td>
<td>-0.354*</td>
</tr>
<tr>
<td>9. Soc. support</td>
<td>0.260*</td>
<td>0.265*</td>
<td>-0.012</td>
<td>0.500*</td>
<td>-0.358*</td>
<td>-0.141</td>
<td>-0.280*</td>
<td>0.338*</td>
<td>–</td>
<td>-0.394*</td>
</tr>
<tr>
<td>10. Abort</td>
<td>-0.296</td>
<td>-0.236*</td>
<td>-0.057</td>
<td>-0.400*</td>
<td>0.265*</td>
<td>0.130</td>
<td>0.233*</td>
<td>-0.340*</td>
<td>-0.229*</td>
<td>–</td>
</tr>
</tbody>
</table>

*Note. Numbers above the diagonal indicate correlation coefficients for the Down Syndrome group and those below the diagonal indicate correlation coefficients for the muscular dystrophy group.  
*p < 0.05.
the second step also resulted in a significant increase in $R^2$, $R^2 = 0.383$, $F_{chg}(2, 117) = 6.55$, $p = 0.002$. Adding the two POPI sub-scales measuring anticipated rewards (enrichment and family continuity) into the equation on the final step resulted in another significant increase in $R^2$, $R^2 = 0.465$, $F_{chg}(2, 115) = 8.79$, $p < 0.001$. Although family continuity did not emerge as significant, the anticipated personal enrichment associated with parenting a child with Down Syndrome accounted for approximately 5% of the unique variance in willingness to terminate a pregnancy subsequent to a diagnosis of foetal Down Syndrome. Specifically, those who associated less personal rewards with parenting a child with Down Syndrome were more likely to consider terminating a pregnancy subsequent to a diagnosis of Down Syndrome. None of the sub-scale scores reflecting perceived parenting costs contributed to the prediction equation, but the sub-scale scores reflecting the perceived social support for parenting efforts accounted for just over 6% of the unique variance in willingness to terminate such that those respondents who anticipated more social support indicated a lower willingness to consider termination.

For comparison purposes, a similar hierarchical regression was conducted on the sub-sample of respondents who completed the muscular dystrophy version of the questionnaire. After the third step, with all the variables in the equation, $R = 0.52$, $F(6, 90) = 5.62$, $p < 0.001$. Following the introduction of strength of religious beliefs and SADP scores on the first step, $R$ was significantly different from zero, $R^2 = 0.148$, $F(2, 94) = 8.17$, $p = 0.001$. The addition of scores on the POPI sub-scales measuring perceived social support and the anticipated parenting costs of isolation on the second step did not result in a significant increase in $R$, $R^2 = 0.169$, $F_{chg}(2, 92) = 1.18$, $p = 0.311$. Adding the two POPI sub-scales measuring anticipated rewards (enrichment and family continuity) into the equation on the final step resulted in another significant increase in $R$, $R^2 = 0.274$, $F_{chg}(2, 90) = 6.46$, $p = 0.002$. After the influence of the non-POPI measures was removed, only the personal enrichment rewards and the continuity of self and family associated with parenting a child with muscular dystrophy accounted for unique variance (approximately 3% of the variance each) in willingness to terminate a pregnancy subsequent to a diagnosis of foetal muscular dystrophy.
Discussion

Within the present sample the normative perceptions of parenting a child with either a physical (muscular dystrophy) or a cognitive (Down Syndrome) disability was less positive than those of parenting a child with no disability, both in terms of heightened costs and lack of rewards. However, although parenting a child with Down Syndrome was perceived as equally taxing (emotionally, financially, physically, etc.) as parenting a child with a physical disability, the former was associated with significantly fewer parental rewards, both in terms of personal enrichment and the potential for family continuity. It appears that parenting a child with Down Syndrome is viewed as less personally rewarding, but not inherently more costly, than parenting a child with a physical disability.

The results of this study lead to the conclusion that the perceptions of parenting a child with a disability do contribute to the willingness to terminate a pregnancy following a prenatal diagnosis for either a physical (muscular dystrophy) or a mental (Down Syndrome) disability. However, although lowered personal enrichment associated with parenting was predictive of an increased willingness to consider termination in both disability conditions, the anticipated parenting costs were predictive in neither condition.

These results provide further support for prior findings that it is the loss of anticipated parenting rewards, rather than the expectation of heightened costs, that influence parenting decisions (Lawson, 2001, 2004). The relatively large mean values on the POPI sub-scales targeting anticipated costs associated with parenting (instrumental costs, commitment and isolation) presented in Table 2 suggest that the respondents were evaluating these as salient domains of parenting, and that these costs were perceived as being enhanced when the target child had a disability. However, the finding that these costs of parenting do not influence motivations to undergo selective abortion indicates that these costs may be perceived as being a part of the parenting experience by all individuals to the same degree. In other words, parenting a child with a disability may simply be accepted as being more costly, and it is the perceived personal rewards that distinguish those who are willing to consider selective abortion and those who are not. Alternatively, it may be that the costs of parenting a child with a disability, although recognized, are not salient to hypothetical reproductive decisions. When faced with an actual foetal diagnosis, the impact of potential parenting costs may become more relevant to individuals and therefore may play a role in decisions regarding termination. Future research examining the influence of the expectations of parenting on actual decisions regarding termination for foetal disability is necessary.

The fact that the respondents in the present study did not indicate a greater willingness to consider termination for Down Syndrome than for muscular dystrophy, and that they evidenced relatively low rates of willingness across either disability condition, although consistent with previous findings, may also be a result of the hypothetical nature of the study. Past community surveys conclude that the majority of individuals indicate that they would not consider termination in response to hypothetical scenarios involving prenatal diagnoses even thought this does not correspond with actual clinical rates of selective abortion following a diagnosis (Evers-Kiebooms et al., 1993; Green et al., 1993; Singer, 1993; Wertz et al., 1991). That these ‘hypothetical’ rates diverge from actual rates for termination is likely due to the fact that individuals responding to hypothetical scenarios underestimate the extent to which they would actually undergo a termination for foetal Down Syndrome (Huys
et al., 1992; Singer, 1993). In a hypothetical scenario, the personal relevance of the situation is not as salient as it is in real life situations and the tendency is for individuals to report intended behaviours that represent an ideal version of how they like to think they would behave. However, when confronted with an actual diagnosis, the impact on potential imagined futures for self and family likely become more salient (Huys et al., 1992), resulting in an increased propensity to choose termination. Given that the present study revealed relatively strong stereotypes of parenting that differ according to disability status, and that these stereotypes differentially predict willingness to consider selective abortion in response to a hypothetical scenario, it is likely that the actual effect of these factors is stronger than these results suggest.

Comparing the outcomes of the two regression analyses highlights important differences between the factors which predict willingness to consider selective abortion for Down Syndrome versus muscular dystrophy. Specifically, attitudes toward persons with disabilities accounted for much more unique variance in relation to likelihood of aborting a foetus diagnosed with Down Syndrome as compared to muscular dystrophy (19.7% versus 4.2%, respectively). Although the SADP is designed to measure global attitudes towards persons with disabilities as a group, it is possible that respondents were answering on the basis of the disability targeted in their version of the questionnaire. That is, those assigned to the Down Syndrome version may have been ‘primed’ to think about Down Syndrome and may have based their responses on their attitudes toward individuals with Down Syndrome in specific, and likewise for the individuals assigned to the muscular dystrophy version. The fact that these two groups differed in their overall SADP scores seems to substantiate this possibility, as there would be no reason to suspect that one group would have, a priori, more negative attitudes towards persons with disabilities than the other. The finding that individuals randomly assigned to the Down Syndrome version evidenced significantly lower SADP scores, reflecting more negative attitudes, than did those assigned to the muscular dystrophy version suggests that responses were being made with the specific target disability in mind. This further supports the proposition that the societal stereotypes regarding persons with Down Syndrome are more negative than those toward persons with a physical disorder such as muscular dystrophy.

A second important difference emerging from a comparison of the regression analyses is that the social support that one anticipates to be available from friends, family and community while parenting a child with Down Syndrome accounts for almost 7% of the variance in selective abortion decisions, while it is non-significant in predicting termination decisions in relation to muscular dystrophy. These two groups do not significantly differ in the mean level of social support they perceive would be available to them while parenting the target child, and yet lack of social support is predictive of willingness to selectively abort in one instance and not the other. Future research should examine the societal perceptions around parenting a child with Down Syndrome that relate to needed social support in order to determine why perceived available social support might be so salient in decisions regarding selective abortion of a foetus with Down Syndrome. Is social support perceived to be more important when parenting a child with Down Syndrome as compared to a child with a physical disability? Or is this further evidence of an enhanced social stigma associated with parenting a child with a cognitive disability?

The majority of respondents indicated that they had little or no personal familiarity with persons with either Down Syndrome or muscular dystrophy. This begs the
question of upon what they are basing their perceptions of parenting children with these conditions. Future research should investigate the extent to which the dominant stereotypes of parenting children with diseases or disabilities coincide with the lived experiences of parents who are actually raising such children. In the specific case of Down Syndrome, previous research has concluded that parents of children with Down Syndrome do not perceive the experience to be as negative as the dominant stereotypes revealed in the present study. Specifically, parents of children with Down Syndrome tend to rate their child as more behaviourally and socially functional than do parents of children with other cognitive disorders or disabilities (Kasari & Hodapp, 1996; Dykens & Kasari, 1997). Further, these parents also report experiencing more social support and less familial stress (Kasari & Hodapp, 1996).

If the dominant perceptions revealed in the present study are unrealistically negative, as it appears they may be, especially with regards to personal parenting rewards and necessary social support, it is possible that many individuals faced with prenatal diagnosis of Down Syndrome may be making their decisions regarding selective abortion on misguided stereotypes. This again highlights the necessity of examining the perceptions of parenting children with disabilities amongst individuals who are faced with decisions regarding prenatal testing and selective termination in a current pregnancy in order to determine whether the present findings generalize from hypothetical scenarios to actual situations.

Sampling limitations

The fact that the present sample was drawn from a population of university employees may raise caution regarding the ability to generalize the results in that university employees may differ from the general population with regards to both demographics and relevant attitudes. In order to examine this issue, the sample demographics were compared with the most recent complete Canadian census data (Statistics Canada, 1999). This comparison revealed that the sample is in rough correspondence with the Canadian population on salient characteristics such as mean age (40.3 years for Canadians age 18 to 65 versus a sample average of 42.3 years) and marital status (78% of the population is married versus 75.6% of the sample). Even though the mean age of the present sample is representative of the population, the fact remains that the age is relatively high for a study involving reproductive decisions and thus might be skewing the results. However, statistical analysis of this issue revealed that age was not significantly correlated with the study variables (with the exception of a negative relation with continuity of self and family within the Down Syndrome group and a negative correlation with perceived social support in the muscular dystrophy group). This lack of relationship suggests that these attitudes are relatively constant across age, indicating not only that the high age of the sample is not overly biasing the results but also that the attitudes revealed within the present study represent robust and dominant societal stereotypes.

The present sample is more educated than the Canadian population (59.6% has a university degree versus 40% of the population which has some university education). The potentially biasing influence of this highly educated sample was further investigated because it is feasible that highly educated individuals might hold more negative attitudes toward parenting a child with an intellectual disability such as Down Syndrome. The distribution of education represented in the sample allowed for a comparison of responses across education levels with each target disability group.
Education was found to have no relation to any of the study variables (attitudes towards persons with disabilities, perceptions of parenting sub-scales and likelihood of selective abortion) within the Down Syndrome group. The lack of significant differences across education levels indicates that the high level of education is not systematically biasing the results. This also further supports the conclusion that this study has tapped into robust societal stereotypes that are consistent and generalizable across demographic strata.

The racial composition of the present sample was predominantly Caucasian, and this may limit the extent to which the findings may generalize. Past research has concluded that Caucasian couples view prenatal testing more favourably, are more likely to undergo prenatal testing and are more likely to selectively abort following a foetal diagnosis than couples from other racial backgrounds (Green et al., 1993; Hamerton et al., 1993). Future research should examine cultural differences in the perceptions of parenting a child with a disability as the role of culture in forming expectations of the parenting experience may contribute not only to dominant cultural stereotypes regarding children with disabilities but also to selective reproductive decisions.

**Implications of findings**

The findings suggest that the perceptions of parenting a child with a disability are less positive than those of parenting a child without a disability, especially with regards to the associated parental rewards. This appears to be accentuated in the case of Down Syndrome. Although the reported expectations of the parenting experience were not overwhelmingly negative, the finding that there are significant differences between the target groups is cause for concern, especially given that the majority of respondents had no personal experience with persons with Down Syndrome. This suggests that the views of a large number of people are based on stereotypes rather than first hand knowledge. Community education efforts aimed towards these stereotypic beliefs regarding parenting may help to moderate the social prejudice experienced by individuals with Down Syndrome and may reduce the likelihood that many prospective parents are basing their decisions regarding selective abortion on inaccurate perceptions of what is involved in raising a child with Down Syndrome.

The fact that less positive expectations of the experience of parenting a child with Down Syndrome appear to be predictive of selective abortion decisions also underscores the importance of including these aspects in medical counselling protocols. Current prenatal testing information protocols focus on transmitting risk related information, such as the probabilities of abnormalities being detected and the risks associated with testing procedures; rarely is information regarding the experiences of parents raising a child with Down Syndrome relayed to those contemplating prenatal diagnosis and selective termination. The observed relationship between perceptions of parenting a child with Down Syndrome and willingness to terminate subsequent to a prenatal diagnosis suggests that this is a salient factor for many individuals, and including a realistic discussion of these issues within medical protocols would enable prospective couples to make more informed choices.

**Acknowledgements**

This research was supported by a Social Sciences and Humanities Research Council grant (no. 410-2002-0901).
References


