

The Portrayal of Down Syndrome in Prenatal Screening Information Pamphlets

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Abstract

Objective: To examine the information about Down syndrome (DS) provided to pregnant women in Canada through a content analysis of prenatal screening information pamphlets.

Methods: Prenatal screening information pamphlets were requested from Canadian prenatal testing centres. In total, 17 pamphlets were received (response rate = 65%). Statements presenting information descriptive of DS were identified from the pamphlets, and a content analysis was carried out. Specifically, each statement was analyzed with respect to both the content and the valence of the information presented on the basis of predetermined decision rules. To enhance reliability, four independent raters reviewed each statement, and any differences in coding were resolved through discussion.

Results: In total, 158 statements descriptive of DS were extracted from the pamphlets. The categorical analysis revealed that 91% of the extracted statements emphasized medical or clinical information about DS, whereas only 9% of the statements relayed information pertaining to psychosocial issues. The valence analysis revealed that nearly one half of the statements portrayed a negative message pertaining to DS, while only 2.4% of the statements conveyed a positive image of DS.

Conclusion: The pamphlets provided to pregnant women do not appear to present a comprehensive, balanced portrayal of DS, which may serve to limit informed decision-making.

Résumé

Objectif : Examiner les renseignements au sujet du syndrome de Down (SD) qui sont offerts aux femmes enceintes au Canada, par l'intermédiaire d'une analyse du contenu de dépliants traitant du dépistage prénatal.

Méthodes : Des dépliants traitant du dépistage prénatal ont été demandés auprès de divers centres canadiens de dépistage prénatal. Au total, nous avons reçu 17 dépliants (taux de réponse = 65 %). Les énoncés présentant des renseignements

qui décrivaient le SD ont été tirés de ces dépliants et nous avons par la suite procédé à l'analyse de leur contenu. Plus particulièrement, chacun des énoncés a été analysé en fonction de son contenu et de la valence des renseignements offerts, conformément à des règles de décision déterminées à l'avance. Pour rehausser la fiabilité, quatre évaluateurs indépendants ont analysé chacun des énoncés et les différences de codage ont été, le cas échéant, résolues au moyen de discussions.

Résultats : Au total, 158 énoncés décrivant le SD ont été extraits des dépliants reçus. L'analyse catégorique a révélé que 91 % des énoncés extraits mettaient l'accent sur des renseignements médicaux ou cliniques au sujet du SD, tandis que seulement 9 % des énoncés offraient des renseignements traitant des aspects psychosociaux du SD. L'analyse de la valence a révélé que près de la moitié des énoncés offraient un message négatif à l'égard du SD, tandis que seulement 2,4 % des énoncés en offraient une image positive.

Conclusion : Les dépliants offerts aux femmes enceintes ne semblent pas présenter un portrait exhaustif et nuancé du SD, ce qui pourrait avoir pour effet de limiter la capacité de celles-ci à prendre une décision éclairée.

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INTRODUCTION

Prenatal screening has become a routine aspect of prenatal care.^{1,2} Historically, prenatal screening was offered to women with an increased chance of fetal anomalies on the basis of their family history and advanced maternal age.^{3,4} However, since 2007, Canadian clinical practice guidelines have recommended that the offer of non-invasive screening for Down syndrome (DS) be a routine component of prenatal care for all pregnant women.^{1,4} One implication of universal screening is that more Canadian women than ever face decisions about screening, testing, and pregnancy termination, particularly in relation to DS. The current SOGC guidelines¹ state that screening is to be directed towards conditions “serious enough to warrant intervention,” and it is worth noting that, in the case of DS, there are no therapeutic

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interventions available. Therefore, the options available to women following a diagnosis are limited to preparing for life with a disabled child, planning for the child's adoption, or terminating the pregnancy.⁵

Prenatal screening and diagnostic testing procedures are most often promoted as means of enhancing reproductive choice for women.^{5,6} The SOGC practice guidelines¹ state that screening programs must "include the provision of understandable information . . . to ensure informed decision-making," and specifically recommends that such counselling be non-directive and respectful of women's choices. However, although informed choice and decision-making autonomy are foundational principles for all screening programs as laid out by the Canadian guidelines, there is concern that the materials given to pregnant women as part of the medical protocols may not facilitate fully informed decision-making. Because the prenatal screening guidelines focus specifically on the detection of DS,¹ disability advocates have expressed concern about the DS-related information provided to pregnant women facing these decisions. The Canadian Down Syndrome Society concludes that the "decision-making opportunity is flawed" if pregnant women are not provided with "fair, balanced, and value-neutral information about Down syndrome and the realities of life with a disability."⁷ To address this issue empirically, the current study examined the DS-related information contained in Canadian prenatal screening information pamphlets.

Although prenatal screening and testing are promoted as means of enhancing reproductive autonomy, it has been argued that selective termination can be construed as a discriminatory practice if it is based upon misinformation about persons with disabilities in general or about parenting children with disabilities in particular.⁸⁻¹⁰ In fact, advocacy groups have long asserted that misinformation and misunderstandings about disability may underlie the use of prenatal screening and/or testing and selective abortion for some women.^{7,10,11}

Supporting this assertion, many people view parenting a child with DS as relatively unrewarding,^{12,13} and this perception is related to willingness to consider selective abortion for DS.¹⁴ However, approximately one half of the people surveyed in these studies also report having no personal familiarity with individuals with DS, raising the possibility that their views may be misinformed. In fact, those who have personal experience with individuals with DS have been found to hold more positive views of the rewarding aspects of parenting a child with DS and to be less willing to consider selective abortion for DS.¹⁴ These findings raise the possibility that, for many

individuals, their initial attitudes about prenatal screening, testing, and selective abortion may be influenced more by stereotypes and misinformation about DS than by informed experience. This underscores the importance of the information provided to pregnant women receiving prenatal health care.

Medical health professionals occupy a central role in disseminating information to patients. The personal attributes, attitudes, beliefs, and communication styles of physicians can influence the screening choices made by women.¹⁵⁻¹⁷ There is documented concern that the information provided by medical professionals during prenatal counselling may often be subtly biased towards encouraging the uptake of screening, testing, and subsequent selective abortion.^{6,18-21} Often screening is presented as the presumed course of action, and the need for detailed discussion of the procedures, beyond the benefits, is minimized.^{18,21,22} Such routinization of screening in prenatal care may serve to undermine the process of informed choice.^{6,23,24} Further, the information provided to pregnant women in medical protocols tends to focus on technical and medical aspects of the procedures while neglecting to address misperceptions or stereotypes about conditions such as DS.^{7,23-25} When DS-related information is relayed, women are most often provided with "medical tragedy" information pertaining only to the medical complications associated with DS,^{26,27} and balanced information about parents' experiences of raising a child with a disability is rarely relayed.^{7,27}

The majority of physicians spend less than five minutes discussing prenatal screening with each patient.^{2,25} In many cases, the main source of information for women considering prenatal screening is an information pamphlet that they are encouraged to read on their own.²⁷⁻²⁹ These pamphlets, in particular, have been criticized for being heavily weighted towards a negative portrayal of DS.^{7,27,29} A review of screening pamphlets distributed to prenatal patients in the United Kingdom revealed that one third did not contain any descriptive information pertaining to DS. When DS-related information was present, it was most often focused on medical issues and negative in nature.³⁰ Information pamphlets presenting a negative portrayal of DS have been found to increase intentions to terminate a pregnancy on the basis of DS.²⁹

In fact, portrayals of DS have been found to vary depending upon when the information is provided. A direct comparison between the portrayal of DS in pamphlets provided to women contemplating screening and the portrayal of DS in pamphlets provided to women following the birth of a child with DS revealed that the former contained

primarily negative DS-related information, while the latter provided primarily positive DS-related information.³⁰ In essence, prenatal pamphlets appear to lack the positive DS-related information that tends to dominate pamphlets provided after the birth of a child with DS. Such biases in the presentation of information may hinder informed reproductive decision-making, especially given the lack of personal knowledge of DS and the prevailing negative societal views of parenting a child with DS.^{13,31} Not surprisingly, a substantial number of women report that they do not feel adequately informed by current medical protocols to make decisions about screening and testing,³² and they specifically express concern that they have very little substantial knowledge about DS.^{31,33}

The concern that the information given to pregnant women in current medical protocols may not facilitate fully informed decision-making highlights the need for further investigation of the content of prenatal screening information. The aim of the present study was to examine the DS-related information in the prenatal screening information pamphlets provided to pregnant women in Canada.

METHODS

Information pamphlets introducing prenatal screening to pregnant women were requested from Canadian prenatal screening centres and clinics (N = 26). The list of Canadian prenatal screening centres was obtained from the appendix of the 2007 SOGC Clinical Practice Guideline "Prenatal Screening for Fetal Aneuploidy."²⁴ The screening centres and clinics in Quebec were excluded from this initial investigation because of the pragmatic constraints of translation. An introductory letter providing an overview of the study was mailed to each screening centre and clinic along with a request for the written information materials that the centre provides to pregnant women who are considering prenatal screening. A stamped, self-addressed envelope was included in the introductory package to facilitate the return of the written materials to the investigators. Reminder telephone calls were made to those screening centres that did not respond within two weeks after the mailing of the request letters. Finally, attempts were made to locate electronic versions of patient pamphlets available from non-responding centre websites. In total, 17 pamphlets were collected, representing five provinces: Ontario (n = 11), Nova Scotia (n = 2), Alberta (n = 2), Manitoba (n = 1), and Saskatchewan (n = 1). The overall response rate from the invited centres was 65%. The information pamphlets were each read by two independent raters and each statement containing a reference to DS

was extracted. Each statement was then coded as being either DS-descriptive (i.e., providing specific descriptive information about DS) or procedure-descriptive (i.e., providing specific descriptive information about the screening procedure and merely presenting DS as a specific characteristic in the screening panel). Because the focus of the present study was to examine the portrayal of DS in these pamphlets, the procedure-descriptive statements underwent no further analysis.

A two-phase content analysis was conducted on each DS-descriptive statement. The first phase consisted of a categorical analysis to determine the type of information about DS relayed in the statement. The second phase focused on examining the valence of each statement to determine whether it portrayed DS in a negative, neutral, or positive manner. Three additional independent raters reviewed each determination (i.e., the categorical and valence decisions for each statement) to enhance the reliability of these analyses. Any differences were resolved through discussion.

Following the analytic procedure of Bryant et al.,³⁰ statements were defined as distinct pieces of information about DS. Thus it was possible to extract several statements from one sentence. The categorical analysis involved examining each identified DS-related statement in order to code the type or class of information presented (e.g., medical, prevalence). Using predetermined decision-rules, we coded each statement to one of 15 distinct categories of information (Table 1). The coding process was mutually exclusive, such that each statement was coded to only one information category.

Thirteen of the categories were predefined by Bryant et al.³⁰ Two additional categories (parental education about DS, and post-diagnosis decisions) emerged during the content analysis and were deemed salient enough to include as distinct categories. The 15 categories, with illustrative statements extracted from the pamphlets, are listed in Table 1.

The valence analysis qualitatively examined the extracted DS-related information for negative, neutral, or positive language. The units of analysis for the valence-related information were full sentences, in contrast to the sentence fragments (statements) used in the analysis of the categorical information. Specifically, full sentences related to DS were examined using a modified version of the classification rules employed by Bryant et al.³⁰ to determine whether they conveyed a negative, neutral, or positive message about DS. Sentences were categorized as "positive" if the focus was on the following:

Table 1. Aggregated prevalence of information categories in statements describing Down syndrome

Information category	Classification decision rules statements referring to:	Example statement	Present	
			n/17	%
Population prevalence	Probability of having a baby with DS (chance, risk, probability, age of mother)	...about 1 in 800 babies is born with DS	15	88
Medical	Health or medical issues (e.g., heart, hearing, stomach, bowel, thyroid, vision)	...medical problems such as heart defects	13	77
Intellectual disability	Cognitive, intellectual or mental development	...characterized by mental retardation	13	77
Genetic origins	Family history, chromosomes or genetics	...caused by an extra chromosome	11	69
Physical appearance	Facial or physical appearance of individuals with DS, including references to physical disabilities or characteristics	...abnormal facial features	10	59
Treatment for DS	Available (or lack of) treatments, cures, or interventions for DS	... no cure	9	53
Prediction of severity	Inability to predict the severity of the medical or intellectual condition of the child prenatally	...no way to predict the severity	8	47
Variation in ability	DS manifests along a spectrum of abilities and challenges	The severity varies from person to person	8	47
Parental education	Available help and supports for families raising a child with DS	...chance to learn about the help that exists	6	35
Post-diagnosis decisions	Options following a diagnosis of DS (i.e., abortion, adoption, parenting)	...you can choose to continue or end the pregnancy	3	18
Education-related issues	Learning- or school-related issues	Resources are available to help...	2	12
Life expectancy	Approximate lifespan	...generally live into their fifties	1	6
Social factors	Employment, living arrangement and independence issues	...live with families or in a group home	1	6
Parenting a child with DS	Aspects of parenting a child with DS, including emotions, expectations, and experiences		0	0
Emotional aspects of DS	Emotional experiences of persons with DS		0	0

1. available treatments, services and supports,
2. educational supports and outcomes,
3. improvements in life expectancy, or
4. the ability of people with DS to experience important life activities.

In contrast, sentences were categorized as “negative” if the focus was on the following:

1. clinical/developmental complications,
2. reduced life expectancy,
3. lack of treatment,
4. reduced quality of life, or
5. descriptions of DS using negatively value-laden terms (e.g., abnormality, problem, defect, handicap, risk).

Finally, sentences were categorized as “neutral” if they contained

1. a balance of both positive and negative aspects as outlined above, or

2. descriptions of DS using neutral terms (e.g., difference, condition, characteristic, chance, probability).

A summary of the classification rules guiding the valence analysis and exemplar statements from each classification is given in Table 2.

Because the data were obtained from materials available in the public domain, the present study was deemed exempt from ethical review.

RESULTS

In total, 371 statements containing a reference to DS were identified in the sample of pamphlets. Of these, 213 (approximately 57%) were categorized as being primarily procedure-descriptive, and the remaining statements (158; 43%) were coded as presenting information descriptive of DS. The analyses and the results that follow focus exclusively on the statements deemed to be descriptive of DS. A summary of the number (and percentages) of

Table 2. Prevalence of negative, neutral, and positive valences in sentences descriptive of Down syndrome

Valence category	Classification criteria	Example statements	%
Negative valence	Focus on: <ul style="list-style-type: none"> • Clinical/developmental complications • Reduced life expectancy • Reduced quality of life • Lack of treatment Sentences containing: <ul style="list-style-type: none"> • Stigmatizing descriptions • Value-laden words such as abnormality, problem, disorder, defect, risk, handicap 	Down syndrome may cause birth defects such as heart defects. The risk is only 1 in 1667 for a 20-year-old woman. All people with Down syndrome have a mental handicap and some physical handicaps.	47.2
Neutral valence	Sentences containing: <ul style="list-style-type: none"> • Both positive and negative aspects • No value-laden terms • Valence-neutral terms such as chance, probability, difference, condition, change 	Each person with Down syndrome is different. The chance of having a child with Down syndrome increases with the mother's age. The extra chromosome causes the variety of differences seen in babies with Down syndrome.	50.4
Positive valence	Sentences referring to: <ul style="list-style-type: none"> • Available services or support • Educational support and outcomes • Life expectancy improvements • The ability of persons with DS to experience important life activities 	Treatment is available for many of these conditions. You will also have the chance to learn about the help that exists for children with Down syndrome. ...you can plan for the birth of your child and find out from others what it is like to raise a child with this condition.	2.4

pamphlets in the sample that contained references to each of the DS-descriptive information categories is provided in Table 1. The DS-descriptive information categories reflected in each individual pamphlet are shown in Table 3.

As can be readily seen from Tables 1 and 3, there was great variation in the representation of the information categories in this sample of pamphlets. The prevalence of DS, associated medical issues, and intellectual disability were the most frequently represented information categories, each appearing in over 75% of the pamphlets. Non-parametric chi-square tests substantiate that these categories were present in a significant majority of the pamphlets (medical problems, $\chi^2 = 4.77$, $df = 1$, $P = 0.029$; intellectual disability, $\chi^2 = 4.77$, $df = 1$, $P = 0.029$; and prevalence in society $\chi^2 = 9.94$, $df = 1$, $P = 0.002$). Information statements about the genetic origins of DS, the typical physical appearance associated with DS, and treatment issues were present in a the next largest number of the pamphlets, while statements focusing on the prognosis and variability of DS were present in just under one half of the pamphlets.

In contrast, the majority of the pamphlets did not contain statements relaying information about post-diagnosis options ($\chi^2 = 7.12$, $df = 1$, $P = 0.008$), average life expectancy ($\chi^2 = 13.24$, $df = 1$, $P < 0.001$), educational development

($\chi^2 = 9.94$, $df = 1$, $P = 0.002$), or social factors ($\chi^2 = 13.24$, $df = 1$, $P < 0.001$). Finally, details specific to parenting a child with DS or to the psychosocial and emotional aspects of DS were absent from all of the pamphlets.

Although no pamphlet contained information representative of all the possible categories, just over one quarter of pamphlets ($n = 5$) encompassed information pertaining to at least one half of the categories (Table 3). Almost one half of the pamphlets ($n = 7$) contained statements pertaining to five, six, or seven distinct information categories, and approximately one fifth of the pamphlets ($n = 3$) contained statements pertaining to only two or three of the DS-related information categories. Finally, although the pamphlets were all intended to provide information about prenatal screening for DS, one pamphlet contained no descriptive information about DS.

In total, 125 DS-related sentences were extracted from the pamphlets and coded for valence (a summary of the classification criteria and exemplar sentences is provided in Table 2). Of these, approximately one half were categorized as neutral ($n = 63$; 50.4%), while just under one half were classified as conveying negative content ($n = 59$; 47.2%). In contrast, only three (2.4%) of the extracted sentences were categorized as conveying a positive message about DS.

Table 3. Presence of Down syndrome-related information categories by pamphlet

Information category	Pamphlet																
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Population prevalence	X	X	X	X	X	X	X	X	X	X	X	X	X	X			X
Medical	X	X	X	X	X		X		X	X	X	X	X		X	X	
Mental retardation	X	X	X	X	X		X		X	X	X	X	X		X	X	
Genetic origins	X	X	X	X	X	X		X		X				X	X	X	
Physical appearance		X		X	X		X		X	X	X		X		X	X	
Treatment for DS	X	X		X	X	X	X		X		X	X					
Prediction of severity					X		X		X	X	X	X	X		X		
Variation in ability	X		X		X		X		X	X		X	X				
Parental education	X				X		X		X			X	X				
Post-diagnosis decisions					X							X	X				
Education-related issues							X		X								
Life expectancy												X					
Social factors										X							
Parenting																	
Emotional aspects																	
Total	7	6	5	6	10	3	9	2	9	7	7	9	8	2	5	5	0

There was diversity in the pamphlets with respect to the valence of the statements. The number of sentences coded as negative in each pamphlet ranged from 0 to 9 (mean 3.5, SD 2.2), while the number coded as neutral ranged from 0 to 7 per pamphlet (mean 3.7, SD 2.5). The three sentences coded as positive in content were extracted from two pamphlets only.

DISCUSSION

From the present analysis, it appears that prenatal screening information pamphlets distributed to expectant parents by Canadian prenatal screening centres may not be providing a comprehensive or balanced portrayal of DS. Specifically, the sample of pamphlets analyzed in the present study focused heavily on relaying information that was biomedical and/or epidemiological in nature. In fact, over three quarters of the pamphlets contained information relating to population probability rates of DS, health issues associated with DS, and intellectual disability. In contrast, a very small minority of the pamphlets relayed information pertaining to psychosocial aspects such as educational, employment, and living arrangement options for people with DS. Most surprising was the finding that only three pamphlets addressed the options available in the event of a diagnosis of fetal DS, and no pamphlets contained any reference to issues related to parenting a child with DS. In addition, the valence analysis indicated that the DS-related information

contained in the pamphlets was predominantly neutral or negative. This pattern of findings corroborates concerns that the information provided to pregnant women tends to focus on technical material^{7,23-25} that emphasizes the medical complications associated with DS.^{26,27,29,30}

The medical issues associated with DS are, of course, highly relevant to expectant couples making reproductive decisions. However, there are other specific categories of information that are also likely salient to decisions about the use of prenatal screening. Prenatal screening allows expectant parents to make decisions about the future of the pregnancy based upon the detection of specific fetal characteristics. In essence, most individuals faced with prenatal screening decisions are motivated to be a parent, but the question at hand is whether they want to be selective about the child that they parent. It is the prospect of parenting a child with a specific characteristic (in this case DS) that drives the use of prenatal screening and testing. Some social commentators contend that misunderstandings about individuals with disabilities and misinformation about parenting children with disabilities form the foundation for the use of prenatal screening.⁷⁻¹¹ Those individuals who have experienced close relationships with individuals with DS tend to hold more positive views both of persons with DS in general and of parenting a child with DS.¹⁴ These individuals also indicate more certainty that they would not make use of selective reproductive technologies to prevent the birth of a child with DS.¹⁴ In

fact, the majority of parents (both adoptive and biological) raising a child with an intellectual disability show evidence of healthy psychological well-being and family functioning,^{34–39} and portray their parenting experience as significantly rewarding.⁴⁰

In contrast, the people most likely to consider selectively aborting a fetus with DS are those who have the least personal experience of persons with DS.¹⁴ Approximately one half of the respondents to recent community and university student surveys revealed that they had no personal experience of people with DS, and this lack of familiarity was associated with adherence to negative stereotypes about DS and the belief that parenting a child with DS would not be personally rewarding.^{12,14} It is possible that for some individuals their negative views of parenting a child with DS and their willingness to abort a fetus diagnosed with DS may be based more on misinformation than on first-hand knowledge of DS or of individuals living with DS.

The potential role of personal unfamiliarity with DS in selective reproduction decisions underscores the importance of providing expectant parents who face prenatal screening decisions with realistic and comprehensive information about the experience of parenting a child with DS. However, the present analysis indicates that information directly addressing the psychosocial aspects of parenting a child with DS is not being delivered via the educational pamphlets developed to aid in prenatal screening decision-making.

Why do prenatal screening information pamphlets focus on medical/technical material and rarely, if ever, address psychosocial issues related to parenting a child with DS? There are several possible explanations. First, medical professionals are instrumental in preparing the pamphlets. As noted by Bryant et al.,³⁰ medical professionals are most knowledgeable about and familiar with the medical and technical information related to prenatal screening. Therefore, it is quite likely that the content of the pamphlets is highly influenced by the knowledge base and expertise of the authors.

It has also been argued that the relative lack of a positive portrayal of DS in medical protocols may reflect implicit negative attitudes towards DS held by many medical professionals^{7,20,21} and an underlying bias towards increasing screening and testing uptake.^{18,19} Lowering the incidence rate of DS births is viewed as a successful outcome for screening programs,⁴¹ and physicians generally view DS-selective termination for DS as the expected decision.⁴²

Second, it may be that the authors of the pamphlets believe that enhancing knowledge of the screening procedure itself should be a priority at this early stage. In the present study, over one half of the information provided in the pamphlets addressed procedure-related issues. However, the pamphlets varied greatly in the ratio of procedural to DS-related information they provided, with one pamphlet containing no material related more to DS than to procedure. Because relatively few women will experience a positive screening result, and substantially fewer of those will receive a subsequent diagnosis of fetal DS,¹ it might be argued that it is not necessary to provide detailed information about parenting a child with DS at this stage. However, even at this early stage prenatal screening is not a procedure undertaken for its own sake, but rather is viewed by women as a means to gain reassurance or to facilitate reproductive decisions.^{31,43} Even though screening is a non-invasive procedure with low physical risk to the pregnant woman or fetus, there can be psychological consequences of undergoing screening. Women who receive a low-probability screening result (and thus are not referred for further diagnostic testing) have been found to show lower prenatal bonding throughout their pregnancy than women who either do not have screening at all or who learn through amniocentesis that the fetus does not have DS.⁴⁴ This has been attributed to the probabilistic nature of screening results that may leave lingering uncertainty over the DS-status of the fetus and a concurrent dissociation from the pregnancy as a coping mechanism.⁴⁴ This emphasizes the relevance and importance of addressing DS-related stereotypes and issues related to parenting a child with DS even at this early stage.

Finally, medical professionals in general, and the authors of the pamphlets specifically, might assume that expectant couples faced with prenatal screening and testing decisions have access to and obtain additional pertinent information outside the material provided in the medical protocols. In fact, medical professionals might believe it inappropriate for medical protocols to highlight psychosocial and parenting issues because they fall outside the traditional realm of medical care. In reality, women identify the quality of the information they receive as central to their screening decisions,⁴⁵ and they further identify their physician as their primary source of useful information during pregnancy.⁴⁶ However, women do recognize that the information given by health care providers is often incomplete.²⁵ As a result, a significant number of women report feeling inadequately informed to make prenatal screening and testing decisions,³² and they specifically note their lack of knowledge about DS as a primary barrier to fully informed decision-making.³³

Regardless of the underlying reasons for the content of the prenatal screening information pamphlets, it appears that these pamphlets are not providing Canadian women with a comprehensive portrayal of DS or the realities of parenting a child with DS. Specifically, the pamphlets were found to focus on providing medical and/or technical information about DS with relatively little reference to the psychosocial lives of either individuals with DS or their parents. Furthermore, stigmatizing descriptions and negative value-laden terms (e.g., risk, abnormality, defect) were often embedded in sentences presenting DS-related information as opposed to more neutral terms (e.g., probability, difference, condition). These findings corroborate the concerns voiced by the Canadian Down Syndrome Society that prenatal information pamphlets do not provide adequate and balanced information about DS and thus may not facilitate informed reproductive decision-making in Canadian women to the greatest extent possible.⁷

Future research should directly examine the informational needs of pregnant women in relation to prenatal screening decisions, specifically their comprehensive understanding of DS and their analysis of the information presented in the information pamphlets currently provided to aid decision-making. In addition, studies should be conducted of the other types of DS-related information that pregnant women receive (e.g., oral information from their physicians) to determine the extent to which the information presented in the pamphlets is augmented in order to foster informed decision-making.

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