Services for children and youth with chronic health conditions: Views of pediatricians in British Columbia

Anton R Miller, Magda Reckxy, Mojgan Ghazirad, Michael Papsdorf and Robert W Armstrong

Abstract

Canadian research on health services for children and youth with chronic health conditions (CHC) is limited. In a postal survey, pediatricians in British Columbia rated the quality and safety of health care services for children with chronic medical conditions (Ch-Med) lower (mean rating ± SD on a seven-point scale: 4.86 ± 1.02) than services for children with acute conditions/injuries (5.97 ± 1.01), and lowest for children with chronic developmental, behavioural and mental health conditions (Ch-DBM, 3.06 ± 1.17). To improve health care services for CHC, respondents especially favoured improving access to community-based services and resources and to medical specialists and specialized facilities, and the implementation of alternative models of care. Respondents indicated that physician care of children with CHC could be enhanced by extending the physician’s role, better integrating medical with other aspects of care and adopting more flexible payment mechanisms. Findings suggest the need for enhancement and innovation in medical services for children with CHC, especially Ch-DBM, but also that solutions need to take account of CHC subcategory, geographic factors and differences in practitioner readiness to embrace change.

Key words: children, chronic health conditions, disabilities, health services, pediatricians

Introduction

Existing health care systems are not well designed to deal effectively with chronic health conditions (CHC)1 although new models of care that enshrine the principles of chronic disease management have been proposed and are being implemented to address the care needs of this population.2-5 These important efforts focus largely on the highly prevalent CHC of adults, such as diabetes, hypertension and cardiovascular disease. Although CHC have been identified as one of the primary challenges to current child health delivery systems and policies,6 there has been little recognition within the policy or research communities of the problem of CHC among children and youth (hereinafter referred to simply as “children”). Up to 18% of all children are affected by a chronic condition affecting physical, mental or developmental health,7 and approximately 6% of children have complex and disabling CHC that require services over time from providers across multiple sectors.8 CHC may have a significant adverse impact on children and families9,10 and care of children with CHC accounts for between 60 and 80% of all child health expenditures.11,12

The difficulties that parents experience in accessing and coordinating services for their children with CHC have been documented13 and health and social policy recommendations for services for children with disabilities have been published,14 but few studies have examined how care providers view services for children with CHC. Pediatricians play a central role in care of children with CHC, both as front-line service providers and advocates. They experience the successes and challenges of the services system on a daily basis and their cooperation is needed for implementation of new initiatives. Community pediatricians devote at least 50% of their consultation time, on average, to care of children with chronic conditions,15 but anecdotal experience suggests that numerous factors may impede the ability of physicians to play a truly integrated role in the broader management of children with CHC.

Chronic disease management models present opportunities for physicians to enhance the care they provide to their adults patients. These models are characterized by care that is planned, structured, evidence-based and continuously evaluated, that explicitly values collaboration between primary and specialist providers and between professional disciplines, that emphasizes prevention and self-management, and that uses information technology.2,5,16 By proposing alternative and innovative ways of providing care, however, such models challenge status quo arrangements and may be resisted or rejected by physicians. There has been little attention to formulating chronic disease models that are suitable for children, though chronic conditions among children present some unique features.17 In this study, we surveyed pediatricians in the Canadian province of British Columbia (BC) to ascertain their perceptions and views...
regarding services for CHC and how services might be improved, and their attitudes towards alternative and innovative models of care for children with CHC.

Methods

Study design and population

The study was conducted via a postal survey of all registered pediatricians in BC. Physicians with a specialty certification in pediatrics were identified from a database held by the College of Physicians and Surgeons of BC. To be considered eligible to participate in the study, physicians needed to be in active pediatric practice in BC and devoting at least 25% of their patient-care hours to ambulatory patients.

Setting

BC’s population of approximately 4.2 million is spread over a large and geographically diverse area, with highest density in the Greater Vancouver Regional District (GVRD). The BC Children’s Hospital - Sunny Hill Health Centre for Children complex (BCCH-SH), located in Vancouver, is the province’s main tertiary care pediatric referral and academic centre and provides specialized medical and supportive services to children and families throughout BC. The administrative responsibility for health services in BC is vested in five regional health authorities and one specialized provincial authority. BC is served by approximately 4,500 general and family physicians, 270 pediatricians and 450 psychiatrists, including an estimated 50 child psychiatrists. General and family practitioners provide for most of children’s primary care needs, with pediatricians and psychiatrists providing mainly consultative services. Most community-based pediatricians are paid on a fee-for-service (FFS) basis, with some also contracting their services on an hourly or part-day basis, known as “sessional arrangements”. An increasing number of hospital-based specialists are in an alternative funding model.

Survey instrument and procedures

A 15-item questionnaire was developed by the authors to cover four topic areas. Topic 1 involved an overall evaluation of health care services for children in BC. Respondents were asked to rate the BC health care system’s ability to provide safe, high-quality care to 1) children with chronic medical conditions (Ch-Med) “such as asthma, diabetes, cancer, and arthritis”; 2) children with chronic developmental, behavioural or mental health conditions (Ch-DBM) “such as development delays and disabilities, behavioural problems, attention-deficit/hyperactivity disorder, fetal alcohol syndrome, and depression”; 3) children with acute and/or life-threatening illnesses and injuries; and 4) healthy children and youth (well-child and preventive care). Topic 2 enquired about seven measures to improve care for children with CHC in BC. Topic 3 covered structural and organizational aspects of the community care of a child with CHC, using a series of linked questions about physician roles, remuneration and care setting. Topic 4 sought views on the most appropriate role for child psychiatrists in care of children with chronic behavioural, emotional and mental health problems.

CHC were defined as “associated with limitation of functions, disfigurement, dependency on medication, special diet or medical technology for functioning or control of the condition, or need for more than typical use of medical or related services, or need for special services over time at home or school.” In recent years, a “non-categorical” approach to the identification and study of CHC among children has been advocated that emphasizes commonalities and consequences among specific conditions. We made a distinction between Ch-Med and Ch-DBM in the questionnaire to explore whether physicians discern differences between classes of chronic conditions in terms of service needs.

Respondents’ views were assessed quantitatively, using five- or seven-point scales to measure ratings of effectiveness or agreement with various statements, and qualitatively through narrative comments. Information was also obtained on pediatrician demographic and practice characteristics, including the proportion of their time engaged in different kinds of clinical and non-clinical activities.

A pilot version of the questionnaire was reviewed and tested by three pediatricians (a community-based generalist, a hospital-based generalist and a hospital-based subspecialist) and a health services researcher with expertise in questionnaire design. Their feedback regarding the tool’s clarity, ease of use and relevance was incorporated into the final version.

Questionnaires, along with a cover letter explaining the study and a stamped return envelope, were mailed to 273 potential participants. A dual-purpose thank you/reminder letter was sent to all potential participants two weeks after the initial mailing and a second questionnaire package was sent two weeks after that to those who had not replied. To check on the eligibility status of physicians who failed to respond, we phoned the offices of physicians whose office addresses raised doubts about their being in active pediatric practice with an ambulatory component.

Statistical analysis

Chi-square tests were used to compare characteristics of participants and non-participants (for whom data were available from the College registry). Paired and independent sample t-tests, between groups and repeated measures analyses of variance (ANOVA), and chi-square tests were conducted to determine the statistical significance of various differences. A significance level of \( p < 0.05 \) was used, except in the blocks of questions under Topic 3, where the Bonferroni correction was applied to adjust for multiple comparisons and maintain the family-wise alpha at 0.05 within each block of items. The effect size estimate, Cohen’s \( d \), was calculated to aid the interpretation of differences in various exploratory analyses, noting the convention that \( d = 0.5 \) represents a medium effect.
Question-specific narrative comments were collected and reviewed by one of the authors (AM), and subjected to an iterative process of thematic analysis. Because there was considerable overlap of comments from one section of the questionnaire to other sections, a group of three reviewers worked independently to identify predominant, overarching themes from the survey as a whole, based on robustness of appearance of comments within and across sections and questions. The group then defined a set of overarching themes by consensus.

Results

Participants

Of the 273 questionnaires mailed, 186 were returned: 119 fully completed, 4 not completed and 63 indicating that the respondents did not meet eligibility criteria for participation. Amongst the 87 physicians who did not return a questionnaire, 13 were eventually deemed ineligible to participate and the remaining 74 were classified as eligible non-participants. The participation rate among eligible pediatricians was therefore 60.4% (119/197).

Demographic and practice characteristics of survey participants (N=119) are presented in Table 1, alongside available data on eligible non-participants (N=78). No statistically significant differences were found on any of the variables. Analysis of demographic data showed a high degree of overlap between pediatrician type and practice setting. Almost all general pediatricians (65/68; 96%) were based outside of the BCCH-SH tertiary referral centre area. Most subspecialist pediatricians (40/51; 78%) were based at BCCH-SH, with the remainder distributed almost equally between GVRD and other addresses. Given this overlap, we elected to use practice setting rather than pediatrician type in further subgroup analyses.

Topic 1. Overall evaluation of health care services for children in BC

Pediatricians rated the BC health care system as highly effective in its ability to provide safe, high-quality care to children with acute and/or life threatening conditions (mean rating ± SD: 5.97 ± 1.01, on a seven-point scale), significantly less effective for children with Ch-Med (4.86 ± 1.02; see Figure 1 for statistical relationships) and least effective of all for children with Ch-DBM (3.06 ± 1.17). Ratings for well-child and preventive care were intermediate (4.26 ± 1.29), but not analyzed further as this aspect of care was not a primary focus in this study.

Pediatricians who spent more than the median amount of time caring for children with Ch-DBM rated the quality of services for Ch-DBM lower than those who spent less time (2.76 ± 1.21 vs. 3.32 ± 1.07, respectively; t = 2.64; p = 0.009; d = 0.49).

An interesting, though statistically non-significant, trend was also observed for incrementally lower ratings of care of Ch-DBM with increasing remoteness from the tertiary referral centre. Tertiary referral centre pediatricians rated care of this population at 3.34 (± 1.18), compared with 3.05 (± 1.28) for GVRD pediatricians and 2.76 (± 0.98) for pediatricians practicing in other areas (F [2, 114] = 2.5; p = 0.087).

Topic 2. Measures to improve the care of children with CHC in BC

Pediatricians responded favorably to all seven measures presented as possible ways to help improve the care of children with CHC in BC (Table 2), but three options were rated as more effective than the others (overall F[6,103] = 26.987, p < 0.001). The measure “Improving access to community-based assessment and treatment services and supportive resources” was rated significantly higher.

Table 1: Characteristics of survey participants and eligible non-participants and chi-square significance of differences

<table>
<thead>
<tr>
<th>Study participants (N=119)</th>
<th>Eligible non-participants (N=78)</th>
<th>p-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex (% female)</td>
<td>48 (40.3)</td>
<td>30 (38.5)</td>
</tr>
<tr>
<td>Years since MD graduation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ 20</td>
<td>56 (47.1)</td>
<td>30 (38.5)</td>
</tr>
<tr>
<td>&gt; 20</td>
<td>63 (52.9)</td>
<td>48 (61.5)</td>
</tr>
<tr>
<td>Type of pediatrician</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General pediatrician</td>
<td>68 (57.1)</td>
<td>45 (57.7)</td>
</tr>
<tr>
<td>Subspecialty pediatrician</td>
<td>51 (42.9)</td>
<td>27 (34.6)</td>
</tr>
<tr>
<td>Unknown</td>
<td>6 (7.70)</td>
<td>6 (7.70)</td>
</tr>
<tr>
<td>Practice setting by health authority</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provincial health services authority</td>
<td>43 (36.1)</td>
<td>23 (29.5)</td>
</tr>
<tr>
<td>Vancouver Coastal Health Authority</td>
<td>24 (20.2)</td>
<td>21 (26.9)</td>
</tr>
<tr>
<td>Fraser Health Authority</td>
<td>20 (16.8)</td>
<td>16 (20.5)</td>
</tr>
<tr>
<td>Other health authority (Northern, Interior, Vancouver Island)</td>
<td>32 (26.9)</td>
<td>18 (23.1)</td>
</tr>
<tr>
<td>Practice setting by office address</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tertiary referral center (BCCH-SH**)</td>
<td>43 (36.1)</td>
<td>24 (30.8)</td>
</tr>
<tr>
<td>GVRD***</td>
<td>39 (32.8)</td>
<td>35 (44.9)</td>
</tr>
<tr>
<td>Other</td>
<td>37 (31.1)</td>
<td>19 (24.4)</td>
</tr>
</tbody>
</table>

* Pearson’s chi-square (2-sided)

** British Columbia Children’s Hospital — Sunny Hill Health Centre for Children

***Greater Vancouver Regional District
than all the other options, and the measures “Improving access to medical specialists and specialized facilities” and “Alternative models of care for children with chronic health conditions” were rated higher than all the remaining options. In subgroup analyses limited to the three highest-rated measures, no differences were found by practice setting or by a median split in the amount of time spent in care of Ch-Med or Ch-DBM, with one exception: Pediatricians who spent more time in care of Ch-Med rated the measure “Improving access to medical specialists and specialized facilities” more highly than those who spent less time in care of Ch-Med (5.7 ± 0.93 vs. 5.3 ± 1.15; F [1, 116] = 4.08; p = 0.046; d = 0.38).

A number of respondents offered qualifying comments related to the measure “Alternative models of care for children with CHC”. Comments included caveats regarding the efficiency of alternatives such as interdisciplinary community-based care teams, and the physician’s role and compensation within them. Several respondents suggested that an appropriate role for physicians is as team leaders and educators. Respondents also noted difficulties in recruiting and retaining allied health professionals, especially with expertise in mental health assessment and intervention, to such teams in more remote communities.

When asked to list any other measures that might improve care of children with CHC in BC, a few respondents mentioned the need to acknowledge chronic health conditions; the need for better training and education in chronic conditions for health professionals; and the possibility of integrating and coordinating school services with health and social services.

**Topic 3. Structural and organizational aspects of community care for children with CHC**

Table 3 presents options for improving the structural and organizational aspects of care within four categories, highlighting the “most preferred option” (identified by repeated measures ANOVA) within each category.

1. Respective roles of family physicians, general pediatricians and pediatric (or mental health) subspecialists

Respondents clearly indicated a preference for routine care being provided by a pediatrician, with pediatric subspecialist (for Ch-Med) and/or child psychiatrist (for Ch-DBM) support. However, respondents did not actually disagree that routine care could be provided by a family physician supported by a general pediatrician, with a slightly higher agreement level for this proposition for Ch-Med than Ch-DBM (3.13 ± 1.16 vs. 2.69 ± 1.05, respectively; d = 0.4).

**TABLE 2**

<table>
<thead>
<tr>
<th>Rated effectiveness of proposed measures to improve care for children with chronic health conditions in British Columbia</th>
<th>Mean*</th>
<th>SD</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improving access to community-based assessment and treatment services and supportive resources (e.g., psychologists, counselors, support and info. agencies)</td>
<td>6.10</td>
<td>0.932</td>
<td>&lt; 0.001**</td>
</tr>
<tr>
<td>Improve access to medical specialists and specialized facilities</td>
<td>5.45</td>
<td>1.110</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Alternative models of care for children with chronic health conditions (e.g., interdisciplinary community-based care teams)</td>
<td>5.40</td>
<td>1.195</td>
<td>&lt; 0.001***</td>
</tr>
<tr>
<td>Remuneration by alternatives to fee-for-service billing (e.g., sessional arrangements)</td>
<td>4.88</td>
<td>1.432</td>
<td></td>
</tr>
<tr>
<td>Improved access to or sharing of patient clinical data</td>
<td>4.72</td>
<td>1.402</td>
<td></td>
</tr>
<tr>
<td>Educational interventions aimed at physicians (e.g., continuing medical education/CME)</td>
<td>4.53</td>
<td>1.281</td>
<td></td>
</tr>
<tr>
<td>Changing existing fee-for-service schedules</td>
<td>4.41</td>
<td>1.695</td>
<td></td>
</tr>
</tbody>
</table>

*Rated on seven-point scale “to indicate the extent to which you feel each of the following might help to improve the care of children with chronic health conditions in BC” (1 = not effective; 7 = very effective).

**Mean statistically higher than all others

***Mean statistically higher than all non-bolded options

SD = standard deviation
2. Methods of physician remuneration

Respondents preferred a mixed remuneration arrangement of FFS and sessional payments for physician services to Ch-Med. For Ch-DBM, by contrast, mixed FFS and sessional arrangements were not rated significantly differently from purely sessional payment arrangements. Solely FFS arrangements were the least preferred option, though there was no strong disagreement for this method of remuneration for either Ch-Med (agreement level 2.81 ± 1.18) or Ch-DBM (2.37 ± 1.02; d for Ch-Med vs. Ch-DBM = 0.4).

3. Best care setting for physicians

Respondents strongly agreed that physician care for children with chronic conditions, whether Ch-Med or Ch-DBM, is best provided as part of a team in an interdisciplinary setting, rather than solo from the physician’s office. There was clear disagreement with the notion of a physician working solo to provide care for Ch-DBM.

4. Extent of physician’s role in care of children and youth with CHC

An extended range of care services (i.e., traditional direct care plus case conferencing with other health and non-health professionals) emerged as the “preferred option” for Ch-Med. For Ch-DBM, an extended range and full range of care services (i.e., extended plus gathering and reviewing data from community settings, follow-up contact with other health and non-health professionals) were both preferred options.

In subgroup analyses conducted to examine factors associated with pediatricians’ preferred options for structural and organizational aspects of community care, physician sex, years since MD graduation, practice setting and amount of time spent in care of

### TABLE 3

| Preferred options for British Columbian physicians for structural aspects of care of children with chronic medical (Ch-Med) and chronic developmental, behavioural and mental health conditions (Ch-DBM) |
|-----------------------------|-----------------|-----------------|
| **Physicians’ respective roles:** | **Level of agreement** | **Mean (SD)** |
| | **Ch-Med** | **Ch-DBM** |
| **Best arrangement is routine care by ...** | | |
| family physician supported by general pediatrician | 3.13 (1.16) | 2.69 (1.05) |
| family physician supported by pediatric sub-specialist (or child psychiatrist, for Ch-DBM) | 2.51 (1.08) | 2.68 (1.09) |
| pediatrician supported by pediatric sub-specialist (or child psychiatrist, for Ch-DBM) | 3.98 (1.00) | 4.06 (0.94) |
| **Physician remuneration:** | | |
| **Physician’s time is best remunerated under ...** | | |
| fee-for-service arrangement | 2.81 (1.18) | 2.37 (1.02) |
| sessional arrangement (with appropriate fees) | 3.29 (0.95) | 3.63 (1.02) |
| mixed fee-for-service and sessional arrangements | 3.78 (0.95) | 3.72 (0.98) |
| **Physician care setting:** | | |
| **Irrespective of specialty of physician, best arrangement is physician providing care as ...** | | |
| a solo professional in his/her office | 2.43 (1.00) | 2.10 (0.89) |
| part of a team in an interdisciplinary setting | 4.26 (0.71) | 4.41 (0.66) |
| **Extent of physician’s role:** | | |
| **Irrespective of specialty of physician, physician’s role should be to provide ...** | | |
| traditional direct care** | 3.38 (0.98) | 3.17 (0.96) |
| an extended range of care*** | 3.79 (0.89) | 3.86 (0.85) |
| a full range of direct and indirect care† | 3.44 (1.20) | 3.57 (1.18) |

**Boldface numbers** represent most highly endorsed option within each block of items.

* Rated on five-point scale “to indicate your degree of agreement/disagreement regarding the community care of a child with Ch-Med or Ch-DBM” (1 = strongly disagree, 5 = strongly agree). SD = standard deviation

** Traditional direct care: interview, examination, counseling of patient and family

***Extended range of care: above (**) plus case conferencing with other health and non-health professionals

† Full range of direct and indirect care: above (***) plus gathering and reviewing data from community settings, and follow-up contact with other health and non-health professionals
Ch-Med and Ch-DBM were not related to pediatricians’ most preferred options for these aspects of care. In many instances, however, tertiary-centre-based and community pediatricians disagreed in relation to the least preferred option. Tertiary referral-centre-based pediatricians disagreed more strongly with the propositions that the physician’s time is best remunerated under fee-for-service arrangements; that the best arrangement is a physician providing care as a solo professional from his/her office; and that the physician’s role should be to provide traditional direct care (all p’s < 0.015; data available on request). Moreover, a significant minority of community-based pediatricians, especially those based in the GVRD, expressed agreement that fee-for-service is the best method of remuneration for treating Ch-Med (41.0% for GVRD and 30.6% for other addresses vs. 7.5% for tertiary-centre-based pediatricians; χ² = 21.83, p < .001) and/or with solo care as the best arrangement (27.0% for GVRD and 8.3% for other addresses vs. 5.0% for tertiary centre pediatricians; BCCH; χ² = 26.64, p < .001). Also, a majority of GVRD-based pediatricians (62.5%) expressed agreement that traditional direct care is the best arrangement for treating Ch-Med (vs. 45.9% of pediatricians from other addresses and 39.0% for BCCH; χ² = 15.43, p = .004). The pattern of findings was the same for Ch-DBM, except that there was less support overall for traditional direct care being the best arrangement, and only a trend for GVRD-based pediatricians to express agreement with this option (52.5% of GVRD pediatricians vs. 44.4% of pediatricians from other addresses, and 25.6% of tertiary centre pediatricians; χ² = 8.37, p = .079). Looking at individuals who agreed with more than one of these “conservative” or status quo arrangements, there seems to be a small but significant group of GVRD-based pediatricians (compared with pediatricians from other settings) who are hesitant regarding possible innovative arrangements for Ch-Med (χ² = 16.51, p = .011). In particular, 40% of GVRD-based pediatricians endorsed agreement with two or three of the three arrangements (that fee-for-service, solo care from one’s office and traditional direct care are best options), compared to 21.6% of pediatricians based in other communities and 4.8% of tertiary centre pediatricians. The data suggest the existence of a similar, though smaller, group that favors status quo arrangements for Ch-DBM (χ² = 15.83, p = .015) with 30% of GVRD-based pediatricians endorsing agreement with two or three of these same arrangements, compared to 13.5% of pediatricians based in other communities, and none of the tertiary centre pediatricians.

Amongst the narrative comments collected under Topic 3, many referred to the difficulty of identifying a single “best arrangement” for responsibility for care between family physicians, general pediatricians and subspecialist pediatricians. Respondents noted that much depends on the nature and complexity of the chronic condition and on local expertise and resources. Several respondents, including one who identified his or her practice setting as rural, noted that they and their staff were already providing a full range of services, but without due compensation for “indirect care” activities. Other comments mentioned the importance of multidisciplinary approaches and the possibility of establishing “virtual teams”. Many respondents mentioned an important potential role for nurses (including nurse practitioners and nurse clinicians) in relation to Ch-Med.

**Topic 4. Role of child psychiatrists**

In contrast to the lack of support pediatricians expressed for routine care of children with Ch-Med or Ch-DBM to be provided by family physicians supported by pediatric subspecialists (or child psychiatrists), respondents showed no clear preference when asked whether child psychiatrists should primarily serve as a resource to pediatricians or to family physicians (mean ± SD level of agreement on five-point scale was 3.40 ± 1.18 vs. 3.45 ± 1.05, respectively). This suggests that, in care of children and youth with mental health problems, specifically, pediatricians may be open to family physicians playing an integral role. Some narrative comments alluded to the “bulk of child psychiatry (being) done by general pediatricians …we need child psychiatrists as consultants and educators”, while others mentioned that few general pediatricians have the knowledge or training for this kind of work (mental health), or the desire to be extensively involved in it, at the expense of their “medical” work.

**Overarching themes in narrative comments**

The following themes emerged as predominant across the survey as a whole: 1) the potential importance of interdisciplinarity, community-based team approaches in providing services to this population of children, with the caveats noted previously and with comments that these approaches need to be responsive to local conditions; 2) the desirability of flexible methods of physician remuneration based on geographical location and range of care provided; 3) improving access to care, especially for mental health and subspecialty services, and in rural areas; 4) the place of triage in providing care for children with CHC; 5) the need to support families of affected children by creating networks and linkages in their communities; and 6) measures to augment communication and clinical data transfer between care providers.

In relation to triage, many respondents endorsed a system of care in which family physicians handle routine, intercurrent problems among children with CHC; pediatricians manage the underlying CHC with support from tertiary subspecialists and proper remuneration; and tertiary centres and subspecialists confine themselves to dealing with the most complex of clinical situations. However, a number of respondents expressed frustration with “dysfunctional” triage, in which specialized hospital clinics take on primary and secondary care roles for patients with CHC, and subspecialists such as child psychiatrists manage “straightforward mental health problems such as attention-deficit/hyperactivity disorder”. A preponderance of responses suggested that, with a sound triage model and somewhat better support in their offices, pediatricians could manage Ch-Med without major departures from
current practice, but that meeting the needs of patients with Ch-DBM would require more extensive reorganization and innovation.

**Discussion**

Chronic health conditions among children have received limited attention from health services researchers and planners, especially in Canada. The findings of this survey provide a valuable overview of how front-line pediatricians view the status of health and related services for children with CHC, and possible ways to improve them, as well as clues to understanding pediatricians’ readiness to embrace the newer models of care that might be needed.

Survey participants gave high marks to services for children with acute or life-threatening illnesses, lower marks to services for children with chronic medical problems and lowest marks to services for children with chronic developmental-behavioural and mental health problems. In addition to their overall ratings, participants’ comments throughout the questionnaire reflected concerns about services for children with CHC in general and serious concerns about Ch-DBM in particular. The fact that the lowest ratings for adequacy and quality of services for Ch-DBM came from pediatricians who were most involved in the care of these children adds poignancy and significance to the situation. It is also disturbing that many of the structural and organizational aspects of care that are currently operational were rated as the “least preferred option” for care of children with CHC, and most notably for Ch-DBM.

For Ch-Med, a common pattern of responses in narrative comments indicated that a measured series of non-radical changes would go a long way towards addressing current deficiencies. Such measures include a combination of more support to pediatricians (including the involvement of advanced practice nurses and better access to medical specialists and specialized facilities), a more consistent and efficient system of triage, perhaps a more flexible way of remunerating physicians for the care they provide to these children and families, and better methods of exchanging clinical information. A number of these measures—specifically closer integration of primary and specialist care, closer collaboration and partnership with highly skilled nurses, and better clinical information systems—are components of widely accepted models of chronic disease care for adults.

For Ch-DBM, beyond a more functional system of triage and improvements to the exchange of clinical data, respondents suggested the need for 1) better access to the community-based assessment, treatment and supportive services required for the health and well-being of these children and their families; 2) solutions to a pervasive shortage of professionals with mental health expertise; 3) remuneration methods that would be even more flexible, and perhaps substantially different than for Ch-Med, recognizing the need for substantial indirect care services for this population; and 4) new and alternative models of care, such as interdisciplinary community-based care teams, provided that safeguards to ensure accountability and efficiency were in place. Support for such teams specifically ranged from enthusiastic to guarded in this survey, but interdisciplinary and inter-agency collaboration and integration are becoming standards of care for CHC, particularly for complex and disabling conditions.

Innovative ways to deliver care characterized by continuity and coordination that are being implemented in various parts of the world include the “medical home” concept of community care that promotes care coordination, the “wraparound approach” for children and youth with serious emotional and behavioural conditions, and, in the United Kingdom, assignment to families of key workers.

Present findings support the need to include such possibilities when developing and planning services for children in BC. Another option could be to pilot in smaller communities in BC and Canada modified versions of chronic disease models from adult health care. Because most childhood CHC are not encountered frequently in the practice of an individual general or family physician, “chronic condition teams”, consisting of medical, nursing and allied health service providers and compensated by mixed FFS and sessional arrangements, could provide services within defined geographic catchment areas to children with a range of CHC.

In this study, geographic or practice setting differences also seemed to underpin differences between physicians in their readiness to embrace new roles and reimbursement mechanisms. Although community-based pediatricians overall were not rejecting of alternative and new arrangements for physicians in providing care to CHC, they were relatively more inclined to be accepting of fee-for-service care of children with CHC, and most notably for Ch-DBM, geographic setting and physicians’ readiness for change. Though sometimes difficult to demonstrate statistically, pediatricians in this survey appeared to perceive differences between Ch-Med and Ch-DBM in terms of service needs. Responses to the block of questions on structural and organizational aspects of community care suggest that pediatricians recognize the special challenges of managing Ch-DBM in terms of expertise, time and the need to communicate across settings and disciplines. Furthermore, responses throughout the questionnaire highlighted the issues of access to and coordination of services for this population as most pressing, adding weight to similar concerns articulated previously by parents and policy analysts.
arrangements, solo care from the physician’s office and a traditional “medical role” with these children and families. Tertiary referral centre pediatricians, on the other hand, were the group most rejecting of these status quo arrangements, which pertain to typical community settings. In addition, some community pediatricians appeared to be more strongly supportive of status quo arrangements than others. In particular, a subgroup of community pediatricians situated in reasonably close proximity to the tertiary referral centre for the province, were the most accepting of status quo arrangements. Presumably such a setting allows physicians to enjoy the benefits of traditional practice arrangements, while their patients enjoy access to specialized resources and supports at the hospital. This situation can, however, lead to the kind of “dysfunctional triage” mentioned earlier, and may also undermine the principle of a clearly defined role for primary care and community-based practitioners in care of children with CHC.

The care of children and youth with chronic behavioural, emotional and mental health problems remains a vexing issue for policy makers, and it was notable that pediatricians in BC are not claiming priority over family physicians in obtaining resource support from child psychiatrists. Efforts to instill an awareness and interest in CHC early in the educational curricula of all physicians,36-38 adequate training in child mental health concerns, and appropriate nursing and allied health professional supports are all likely to be helpful in creating interest and confidence amongst community physicians, pediatricians and family physicians, who could potentially work on specialized chronic condition teams and could take a larger role in care of children with mental health issues.39-41

Strengths and limitations

Strengths of this study include the breadth of the survey sample, which is representative of all pediatricians in practice in the province of British Columbia, and a relatively good response rate for a postal survey of physicians.42 The inclusion of a qualitative component allowed for more insight into and expansion of the quantitative data and a wider and more authentic range of views than are possible in a purely forced-choice format.43 Limitations of the study include the fact that this was an original survey, designed in the absence of a validated instrument to cover this content area. Nevertheless, the survey questionnaire has high face validity, especially as an instrument to ascertain respondents’ views in a descriptive way. Though the response rate from eligible participants was quite high, relative to other physician surveys, a 60% response rate also means that the views of a substantial minority of pediatricians in BC were not represented. However, it was reassuring to find no significant differences between participants and non-participants based on background characteristics. Finally, there may be limits to the applicability of our respondents’ views to other jurisdictions.

Conclusion

This survey’s results indicate that a health care system set up to deal with acute illnesses in an otherwise healthy population fails to meet the health needs of children with CHC. There are many challenges to reforming health services for children, especially when considering the alternatives that are increasingly being adopted for adult chronic disease management.2,3 For example, the needs of children with CHC differ from those of adults and only a prototypic chronic disease management model appropriate for children and youth has yet been described (NICHQ Care Model for Child Health). Nevertheless, innovative approaches are increasingly being explored and implemented across the world, and the feasibility of these and other “home-grown” approaches needs to be pursued and examined in Canada.

Pediatricians in BC are clearly concerned about the accessibility and quality of health services for children with CHC, particularly for developmental and mental health. They are generally supportive of change and innovation in the way that services are organized and delivered, and in their own roles, although certain subgroups, defined in part by proximity to the provincial specialized children’s hospital, may be less embracing of change. The findings of this survey also suggest that solutions may need to take account of differences between subcategories of CHC and of geographic factors.

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