

# Health care delivery: Perspectives of young people with chronic illness and their parents

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**Objective:** To identify and compare perceptions of health care service delivery held by young people with chronic illness and their parents.

**Methods:** A convenience sample of young people with chronic illness and their parents were invited to complete a confidential self-report survey. The adolescents were aged 13–18 years inclusive and attended a specialist medical clinic.

**Results:** Participants comprised 53 young people (response rate 88%, 53/60) and 45 parents (response rate 75%, 45/60). Both young people and their parents rate honesty, confidentiality, having good medical knowledge and good listening skills as the most important qualities for a health care provider. Compared to the parent group, fewer young people report the presence of these desired qualities in their current health care provider. A quarter of young people (25%, 13/53) report they do not always trust health professionals to keep their information confidential, and 19% (10/53) of young people report having withheld information from a health professional due to a lack of trust. Some parents and young people would like to discuss a wider range of health topics, including mental health issues, than they currently do with their health provider. Young people and their parents report limited planning with their current health provider for transition to adult health services.

**Conclusions:** Young people with chronic illnesses have significant levels of dissatisfaction with the health care they receive; this has the potential to impact on their use of health care services and their health outcomes. There is a need for increased provider awareness of the important qualities of health care service delivery to young people.

**Key words:** adolescent; chronic illness; health services; quality.

In the last 50 years, the survival of young people with chronic illness has risen dramatically as up to 90% of young people with chronic illness live beyond their 20th birthday.<sup>1</sup> The increasing population of young people with chronic illness or disability are a group with unique health care needs.<sup>1–3</sup> For many of the health professionals who care for them, the ongoing management of the complex medical aspects of care for their chronic condition is very familiar. Unfortunately, the broader psychosocial issues for young people with a chronic illness as they progress through adolescence are less understood.<sup>4–6</sup>

Having a chronic illness as a young person can have a range of impacts on a young person's well-being throughout adolescence and into adulthood. These include increased rates of depression,<sup>7</sup> lack of independence from parents,<sup>7,8</sup> poor vocational education, lower employment rates<sup>8,9</sup> and negative body image.<sup>9,10</sup> The care and support young people receive, in particular the involvement and support of family and school, can influence the prevalence and impact of these negative health outcomes.<sup>1,9,11</sup> Health care providers also play important roles in the lives of young people with chronic illnesses. Those providers that provide a high level of patient satisfaction enhance compliance with treatment regimens and facilitate improved health status.<sup>12–14</sup> Therefore, health care providers need to be aware of the characteristics of health care providers that young people with chronic illness value as well as the wider psychosocial issues that are important to young people with chronic illness.

There is limited published research on the qualities that families and young people with chronic illness value in their

health care providers.<sup>12,15–19</sup> Most research has focused on self-reported health care needs in general population studies of young people who attend school.<sup>20–24</sup> Information is also needed from both the young people with chronic illness and their families. Previous reports suggest while parents and young people often agree on what are important qualities in the delivery of care,<sup>12</sup> parental and adolescent experiences of health care can differ.<sup>18,19</sup>

The aims of this study were to identify the qualities of health care providers and perceptions of health care service valued by young people with chronic illness and their parents.

## METHODS

Eligible subjects were young people with a chronic illness (illness  $\geq 6$  months duration), aged 13–18 years inclusive and living in the greater Auckland region. A convenience sample of young people who attended selected specialist paediatric or adolescent medical clinics and their parents were invited to participate and asked to return completed study questionnaires by mail. A sample size of 50 was used to detect a difference of one (on the rating scales) between the health care delivery beliefs of young people and parents, with a power of 0.8.

A literature review identified key questionnaire items that were included in the development of pen and paper self-report questionnaires for young people and their parents.<sup>12–24</sup> The study questionnaire comprised 110 questions and took 20–30 min to complete. The questionnaire was structured so that respondents selected the most appropriate response, or rated an item on a

five-point scale. The questionnaire enquired about the current health care young people were receiving, what care they would like to receive, and how they felt their health care could be improved. Parents answered similar questions in relation to their child's health care. The questionnaire was pretested for understandability and acceptability by clinicians working with young people, cultural support workers, and by a focus group of young people from the Auckland Adolescent Diabetes Clinic.

Data was double entered for accuracy. All analyses were conducted using SAS version 8.2.<sup>25</sup> Results are presented as median (range) or percentages where appropriate. Spearman's correlations were used to describe correlations between two groups. Differences between groups were tested for significance using the Mann-Whitney *U*-test for unpaired data and Wilcoxon signed rank test for paired data.  $\chi^2$  tests were used to test for differences in proportions.

## RESULTS

Participants were recruited between April and August 2001 at hospital-based outpatient clinics. Of the 60 young people invited to participate, 53 returned a completed questionnaire (response rate 88%). The group of participating young people had a mean age of 16.0 years (range 13–18 years,  $SD \pm 1.3$ ) and included 26 boys and 27 girls. Thirty-nine of the participating young people had diabetes and 14 had other chronic illnesses that included chronic renal failure, obesity, attention deficit hyperactivity disorder and spina bifida. Most of the participating young people (32/51, 63%) reported having had their chronic condition for greater than 5 years. Eight percent (4/51) of the young people had had their chronic illness diagnosed within 6–12 months of the time of survey, 18% (9/51) within 1–3 years and 12% (6/51) within 3–5 years. All young people consented for their parents to complete the survey. The parental response rate was 75% (45/60), with 34 mothers and 11 fathers returning completed questionnaires. No information is available on the non-responding young people or parents.

Most young people reported that the health professional they saw most frequently was a chronic illness clinic provider (35/53, 66%). One quarter (14/53, 26%) nominated their general practitioner as the health professional they saw most frequently. The remainder (4/53, 8%) nominated their school nurse. No young person reported being seen in more than one

hospital clinic. Seven young people (13%) reported that they did not have contact with their general practitioner. Most young people (32/53, 60%) reported being seen by a health professional 3–6 monthly, with five being seen as frequently as weekly. Many young people (22/53, 41%) reported contact with their care providers between visits, mostly by phone.

Young people and their parents were asked to rate the importance of selected health care provider qualities (Table 1). The qualities most highly rated by the young people were honesty, confidentiality, having a good medical knowledge and having good listening skills. Having a provider of the same gender, culture and age were reported to be the least important qualities. Analysis by gender found no significant difference for having a gender-matched provider ( $P = 0.3$ ). Parents and young people rated similar health care provider qualities as important. Parents were significantly more likely than youth to rate as important being able to listen well, having a youth focused service, good local knowledge and convenient appointment times ( $P < 0.01$ ).

When young people rated overall quality of their current health care provider, 87% (46/53) rated their usual health care provider as excellent or above average, 11% (6/53) as average and 2% (1/53) as poor. Within the parent group, 75% (34/45) rated overall service as excellent or above average, 22% (10/45) as average and 2% (1/45) as poor. When comparing individual young person/parent pairs, there was moderate agreement on rating of overall satisfaction ( $r = 0.33$ ,  $P < 0.001$ ).

When asked to identify the presence of selected qualities in their usual health care provider more parents than young people identified the presence of every selected quality with the exception of the provider being in a convenient location ( $P < 0.01$ ) (Table 2). Young people most commonly reported the following characteristics as lacking in their current health care provider: ensuring confidentiality (40/53, 75%), being able to listen well (36/53, 68%) and possessing good medical knowledge (36/53, 68%). All parents (45/45, 100%) reported their child's current provider ensured confidentiality, listened well and possessed good medical knowledge.

Most young people (40/53, 75%) reported having a health professional that they could trust to treat their information confidentially. Conversely, one in four (13/53, 25%) reported that they did not always trust health professionals to keep their information confidential, and a similar number (10/53, 19%) reported having withheld information from a health professional due to a lack of trust. Young people who reported that

**Table 1** Young people and their parents' ratings of desired health care provider qualities

Young person	Rated very important (%)	Parent	Rated very important (%)
Honesty	94 (50/53)	Good listener	100 (45/45)
Confidentiality	91 (48/53)	Honesty	100 (45/45)
Good medical knowledge	87 (46/53)	Good medical knowledge	96 (43/45)
Good listener	85 (45/53)	Confidentiality	93 (42/45)
Cleanliness	75 (40/53)	Convenient appointment times	93 (42/45)
Short wait	72 (38/53)	Cleanliness	91 (41/45)
Convenient appointment times	70 (37/53)	Short wait	87 (39/45)
Easy location to get to	57 (30/53)	Local knowledge	82 (37/45)
Low cost	55 (29/53)	Youth focus service	76 (34/45)
Youth focus service	49 (26/53)	Easy location to get to	71 (32/45)
Local knowledge	42 (22/53)	Low cost	53 (24/45)
Seeing a person of the same gender	34 (18/53)	Seeing a person of the same gender	47 (21/45)
Seeing a person of the same culture	23 (12/53)	Seeing a person of the same culture	40 (18/45)
Seeing a person of similar age	9 (5/53)	Seeing a person of similar age	20 (9/45)

they trusted health professionals also reported higher overall service satisfaction rating ( $r = 0.5$ ,  $P < 0.001$ ).

Table 3 lists the frequency with which young people reported that selected health topics are discussed with them and the topics young people and their parents would like to discuss with their health care provider. From an itemized list, young people and parents identified ways health care providers could improve the provision of health care (Table 4). Young people rated ensuring better confidentiality as more important in improving care than parents ( $\chi^2 = 9.88$ ,  $P = 0.002$ ). Some young people (16/53, 30%) reported that they discussed their mood and feelings with their current health care provider. Significantly more young people and parents reported they would like to discuss these emotional health issues with their current health care provider ( $P < 0.01$ ).

The majority of young people (26/45, 58%) were unable to identify who their health care provider would be in 5-years time. Some young people (12/45, 27%) nominated an adult physician or a general practitioner as their future health care provider. A few young people (7/45, 16%) reported their current paediatric or adolescent specialist would be their future health care provider. Only two young people (2/45, 4%) reported that this had been discussed with them. Of the parents, 21% (9/43) reported not knowing which health professional would be looking after their child's health in the future. Most

parents (26/43, 60%) identified that future health care would be provided by an adult specialist or general practitioner. Several parents (8/43 19%) reported that the current paediatric or adolescent specialist would be the future health care provider.

## DISCUSSION

In this study both young people with chronic illness and their parents report the qualities of honesty, good listening and confidentiality as more important than having a health care provider of the same age, gender or ethnicity. Less young people than parents perceive their health care providers to have the qualities of honesty, good listening and confidentiality. Parents and young people would like to discuss a wider range of health topics with their health care provider. Of particular concern is that mental issues are perceived to be the topic least talked about with their health care provider, but this was an area identified by both young people and their parents that they wanted to discuss more at clinic visits. Young people and their parents report limited planning with their current health provider for transition to adult health services.

Limitations of this study include the small sample size and the use of a convenience sample. Due to this and multiple testing of the data, the results have been interpreted conservatively with a  $P$ -value of  $< 0.01$  being considered significant. Entry into the study required attendance at a specialist health care service, selecting a group of young people who are accessing care. Inclusion of young people who have difficulty accessing health care would have been valuable, but beyond the resources of this study. The reliability of using questionnaires for self report of health beliefs have been widely studied and used in adolescent health research.<sup>26,27</sup> Key informant interviews would have offered the opportunity to gather additional data, but would have involved loss of anonymity, which may have biased young people and parents responses.

This study is similar to past research that found young people value qualities relating to personal characteristics of the provider as more important than those relating to the physical environment of the provider.<sup>28</sup> In addition, the importance of provider cleanliness to young people has been reported.<sup>28</sup> Unlike other studies this study did not find that female adolescents have a preference for female providers.<sup>16,17,24,29</sup> This may be have been due in part to limitations of sample size and the lack of specific focus on women's health issues.

This study supports the findings by Aasland *et al.*<sup>12</sup> who found a trend for children to be less satisfied than their parents with the quality of medical treatment, empathy of health care providers and quality of information. They identified that the amount of chronic family difficulty was predictive of less

**Table 2** Young people and their parents' identification of the usual health care provider's qualities

Quality	Providers reported to have these qualities	
	Young person (%)	Parent (%)
Confidentiality	75 (40/53)	100 (34/34)
Good listener	68 (36/53)	100 (34/34)
Good medical knowledge	68 (36/53)	100 (39/39)
Easy location to get to	64 (34/53)	70 (26/37)
Honest	58 (31/53)	95 (37/39)
Clean	49 (26/53)	100 (38/38)
Same culture	36 (19/53)	69 (25/36)
Same gender	34 (18/53)	53 (18/34)
Youth-focused service	32 (17/53)	94 (29/31)
Convenient appointment times	32 (17/53)	85 (34/40)
Low cost	32 (17/53)	92 (34/37)
Local knowledge of resources	28 (15/53)	91 (21/23)
Short waiting times	21 (11/53)	56 (20/36)
Similar age	2 (1/53)	22 (8/36)

Note not all parents answered all questions.

**Table 3** Issues discussed during clinic appointments

Currently discussed <sup>†</sup>	%	Young people wish to talk about	%	Parents wish to talk about	%
School/education	72 (38/53)	Future plans	60 (32/53)	Mental health	50 (22/44)
Friends/relationships	64 (33/52)	School/education	55 (29/53)	Future plans	47 (21/45)
Future plans	42 (22/52)	Mental health	49 (26/53)	Drug use	43 (18/44)
What job they plan to do	40 (20/52)	What job they plan to do	49 (26/53)	Alcohol use	43 (19/44)
Alcohol use	40 (21/53)	Friends/relationships	47 (25/53)	School/education	43 (19/44)
Drug use	32 (17/53)	Alcohol use	34 (18/53)	What job they plan to do	40 (17/43)
Sexuality	32 (17/52)	Drug use	26 (14/53)	Friends/relationships	36 (16/44)
Mental health	30 (16/52)	Sexuality	25 (13/53)	Sexuality	18 (8/44)

<sup>†</sup>As reported by young people.

**Table 4** Changes young people and their parents recommend to improve the health care provided

Young person	%	Parent	%
Less waiting time	55 (28/51)	Easier to get hold of in emergencies	51 (22/43)
Easier to get hold of in emergencies	47 (24/51)	Less waiting time	33 (14/43)
Better confidentiality	25 (13/51)	Better communication	28 (12/43)
Lower cost	24 (12/51)	Lower cost	19 (8/43)
Better communication	20 (10/51)	Seeing a person of the same sex	19 (8/43)
Seeing a person of the same sex	18 (9/51)	Visiting at school	16 (7/43)
Visiting at home	12 (6/51)	Visiting at home	7 (3/43)
Seeing a person of the same culture	8 (4/51)	Seeing a person of the same culture	7 (3/43)
Visiting at school	6 (3/51)	Seeing a person of the same age	7 (3/43)
Seeing a person of the same age	4 (2/51)	Better confidentiality	2 (1/43)

satisfaction with health care and in the parental group (but not youth), the degree of disability was also an important predictor of satisfaction. While this current study is unable to examine more closely the reasons for the disparities between parental and young peoples perceptions the authors believe it is important, particularly for paediatric services, to be aware that young peoples' perspectives are likely to be less positive than their parents. The high degree of importance young people place on confidentiality in health care has been demonstrated in numerous studies.<sup>2,3,22</sup> In this study, access to confidential care was comparable to other studies that have reported 54–75% of young people had access to confidential health care.<sup>20,22,29</sup> There needs to be increased awareness that many young people will not disclose potentially significant health information if they do not trust providers to keep their health information private and confidential.

The range of issues identified by young people and their parents as important to discuss with their health care provider emphasizes the importance of screening for the broader health issues in all adolescent consultations. The findings of this study support large school-based surveys that find young people have an interest in discussing emotional health issues.<sup>20,21,23</sup> Mental health is a major concern for today's young people and is a topic that many parents and youth would like to discuss with their health care provider, but often they did not have the opportunity to do so.

The importance young people place on health care providers addressing future plans, training and job opportunities for young people with chronic illness and disability has also been confirmed by other researchers.<sup>30</sup> These findings are salient reminders for providers that for many people health care is not limited to 'illness care', but encompasses the wider domains of health as encompassed by the World Health Organization definition of health – 'a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity'.<sup>31</sup>

The desire by young people and their families for health professionals to be easily contactable in emergencies and to have shorter appointment waiting times (as noted in Table 4) confirms previous findings.<sup>15,29</sup> These are both important points to consider in the provision of health care for young people and their families. Young people and their families do not view the health professional's responsibility as limited solely to the appointment times.

This survey highlights a major gap in service planning for transition to adult services. Transfer to adult services is becoming an increasingly common part of paediatric care due to the increasing survival of children with chronic illness and disability, yet of concern this study finds that for most, transition planning is not occurring. Given that evidence suggests that

families need time to adjust to the concept of transitioning to adult services, and that early initiation of transition planning is associated with increased likelihood of success,<sup>30–34</sup> there is much room for improvement in this area.

Although most young people and their parents give high overall satisfaction ratings to their health providers this study identifies several areas for improvement in health care delivery to young people with chronic illness. There is an urgent need for increased health care provider awareness of the important qualities of health service delivery to young people and the implementation of recommendations on workforce training in adolescent health and practise.<sup>35</sup> There are also important service development issues to be addressed by health funders concerning the gaps in the provision of effective transition services for young people with chronic illnesses. Further health service research is warranted focusing on the needs of young people with chronic illness and disability, particularly those who are poor attendees of clinic, to determine ways to improve health care delivery to this potentially high-risk group.

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