

Evaluating treatment outcome in an interdisciplinary pediatric pain service

Susan M Bennett PhD^{1,2}, Christine T Chambers MA², Doria Bellows BSc PT¹, Colleen A Court RN BSN¹,
Elizabeth Huntsman PhD¹, Carolyne Montgomery MD^{1,2}, Tim F Oberlander MD^{1,2},
Michelle Sheriff BSc PT¹, Harold Siden MD¹

SM Bennett, CT Chambers, D Bellows, et al.
**Evaluating treatment outcome in an interdisciplinary
pediatric pain service.**
Pain Res Manage 2000;4(2):169-172.

OBJECTIVE: To provide descriptive data evaluating outcome and treatment satisfaction among former pediatric patients and their parents seen in an interdisciplinary treatment program for complex pain syndromes.

DESIGN: Retrospective telephone interview.

SETTING: Pediatric academic health care centre.

SUBJECTS AND METHODS: A semistructured interview designed for this study was administered by phone with 24 former patients (mean age 15.63 years) and parents, seen over the previous three years in the Complex Pain Consultation Service. Participants provided both qualitative and quantitative information about pre- and post-treatment levels of pain and functioning, achievement of treatment goals and satisfaction with the treatment program.

RESULTS: Findings indicated significantly lower frequency and intensity of pain, as rated by patients, when current pain levels were compared with recalled pretreatment levels. As well, improvements were reported in strategies for managing pain and participation in regular activities of daily living. Satisfaction with the team treatment was generally very high, and most felt that their goals were partially to completely met. Child and parent ratings of outcome and satisfaction were consistent.

CONCLUSIONS: These descriptive data provide preliminary support for the application of an interdisciplinary model to treating disabling complex pain syndromes in children and youths.

Key Words: *Children; Complex pain; Interdisciplinary treatment; Treatment outcome*

Évaluation des résultats d'un programme interdisciplinaire de soulagement de la douleur chez des enfants

OBJECTIF : Recueillir des données descriptives sur le degré de satisfaction de jeunes patients et de leurs parents à l'égard d'un programme de traitement interdisciplinaire pour le soulagement de syndromes douloureux complexes et de ses résultats.

TYPE D'ÉTUDE : Étude rétrospective faite au moyen d'entrevues téléphoniques.

LIEU : Centre universitaire de soins pour enfants.

SUJETS ET MÉTHODE : Une entrevue semi-structurée, conçue pour l'étude, a été menée auprès de 24 jeunes patients (âge moyen : 15,63 ans) et de leurs parents, vus au cours des trois dernières années dans un service de consultation pour syndromes douloureux com-

voir page suivante

¹British Columbia's Children's Hospital and ²The University of British Columbia, Vancouver, British Columbia

Correspondence: Dr Susan Bennett, Department of Psychology, Children's and Women's Health Centre of British Columbia,

4480 Oak Street, Vancouver, British Columbia V6H 3V4. Telephone 604-875-3003, fax 604-875-2770, e-mail sbennett@cw.bc.ca

plexes. Les participants ont fourni des renseignements qualitatifs et quantitatifs sur l'intensité de la douleur avant et après le traitement et le degré de fonctionnement, l'atteinte des objectifs du traitement et le degré de satisfaction à l'égard du programme.

RÉSULTATS : Les résultats indiquent une diminution significative de la douleur et de sa fréquence lorsque les niveaux actuels de douleur, cotés par les patients, étaient comparés aux niveaux remémorés de douleur avant le traitement. De plus, on a noté que les stratégies de soulagement de la douleur et de participation à des activités régulières de

la vie quotidienne se traduisaient par une amélioration de l'état. Le degré de satisfaction à l'égard du traitement en équipe était généralement très élevé, et la plupart des répondants ont déclaré que les objectifs avaient été atteints en tout ou en partie. Il y avait concordance entre les cotes des parents et celles des enfants concernant les résultats et le degré de satisfaction.

CONCLUSIONS : Les données descriptives jettent les assises d'un modèle de traitement interdisciplinaire de syndromes douloureux complexes et invalidants chez les enfants et les jeunes.

The Complex Pain Consultation Service (CPCS) at British Columbia's Children's Hospital, Vancouver, British Columbia comprises an interdisciplinary team of professionals specializing in pediatric pain management, including two developmental pediatricians, a nurse clinician, psychologist, physiotherapist and anesthesiologist. The children and youths referred by physicians to this pain service have a variety of complex chronic pain syndromes. Some are associated with a known chronic illness, injury or pathology, and others are of uncertain origin. Complex chronic pain syndromes in children and youths are challenging to treat effectively for many reasons, including the multifaceted causal factors that need to be addressed, the clinically significant distress or disability in the child or family that can be associated, and developmental considerations (1,2).

Previous survey data with a subgroup of children and youths with complex pain syndromes who had not participated in an integrated team approach to treatment (3) indicated that such pain problems can persist unrelieved at a severe and often continuous level over many years, despite an extensive series of consultations and treatments, with a vast array of health care providers (including traditional as well as alternate and complementary caregivers). Thus, the burden of complex pain for the children, families and the health care system as a whole can be onerous and costly. As a result, these families are often dissatisfied health care consumers.

In the adult pain literature, there is good evidence for the efficacy of an integrated team approach to treating complex chronic pain syndromes with associated disability (4). Over the past decade, several publications in the pediatric literature have described the establishment of analogous pediatric pain services (5,6). Recently, they have been described as the standard of care in a tertiary health care setting (1). However, to date, published data evaluating outcome and consumer satisfaction following treatment in an interdisciplinary pediatric pain service are lacking.

The purpose of this preliminary retrospective interview study was to provide descriptive data evaluating outcome, achievement of goals and treatment satisfaction among former pediatric patients and their parents seen in the CPCS at British Columbia's Children's Hospital. It is the first in a planned series of outcome studies.

Patients in the CPCS are seen simultaneously by the pediatrician, psychologist, nurse clinician and physiotherapist for an initial assessment/consultation session. An individual-

ized, multifaceted treatment plan is then developed, together with the family, and implemented by appropriate team members, in collaboration with local community health care providers. Progress is reviewed at six months and one year. Patient care is coordinated by the nurse clinician. Treatment can include medication; physical therapy approaches such as postural education, aerobic conditioning, muscle strengthening and stretching; cognitive-behavioural strategies for pain and stress management, such as guided imagery and muscle relaxation; or family therapy.

SUBJECTS AND METHODS

Participants

Participants were 24 patients (six boys, 18 girls) seen consecutively in the CPCS over the preceding three years and their mothers. The mean age of patients was 15.63 years (SD 3.13, range nine to 24 years). Interviews were conducted an average of 22.67 months (SD 13.42, range seven to 64 months) after the initial assessment or consultation session with the CPCS team.

Fifteen interviews were completed with both the child and the mother; three were conducted with the child only because the parents were not fluent in English, and six were conducted with the mothers only because the patients were not developmentally capable. Of the patients contacted, only four declined participation.

Based on medical chart review, most (n=13) of the children and youths in this sample presented with pain of uncertain organic etiology; some (n=8) had pain associated with a severe chronic illness, including cystic fibrosis, Duchenne's muscular dystrophy, epidermolysis bullosa, McCune Albright syndrome or astrocytoma, and a few (n=3) had pain resulting from an injury, for example, from a motor vehicle accident.

The majority of patients (n=9) presented with localized musculoskeletal pain (eg, back pain, foot pain); seven presented with headache, five with diffuse musculoskeletal pain and three with dermatological pain (eg, blistering or itch).

Procedure and measure

To ensure confidentiality and reduce demand characteristics, interviews were conducted over the telephone by a graduate research student not affiliated with the CPCS. Interviews were conducted first with mothers, then with children. The interviews took approximately 10 to 15 min. The study was approved by the University of British Columbia and Chil-

dren's and Women's Health Centre Behavioural Research Ethics Committees.

The semistructured interview was designed for the purpose of this study to yield both quantitative and qualitative information; thus, formal reliability and validity are unknown. The actual wording of questions and response options have been incorporated into the text so that readers can assess the face validity of items. Concordance between child and parent data serves as a source of interrater reliability.

Responses to open-ended questions were coded into qualitatively distinct summary categories derived rationally, post hoc, by two independent raters. Any instances of disagreement between raters were resolved by consensus.

RESULTS

Pain intensity

When asked to rate, "How bad was the pain before coming to the CPCS?, using a 0 to 10 scale, with 0 = 'no pain' and 10 = 'worst pain possible'", the mean rating given by children was 8.08 (SD 1.09, range 6 to 10). In contrast, children's mean rating for 'the pain now' was 5.11 (SD 1.75, range 0 to 8). Two children were completely pain-free after treatment. Parents gave a mean rating for pretreatment pain of 7.67 (SD 1.73, range 5 to 10) compared with a post-treatment mean pain rating of 5.74 (SD 2.60, range 0 to 9).

Paired samples *t* tests indicated that the perceived pain intensity after treatment was significantly lower than recalled pretreatment levels, according to both child and parent ratings (child ratings, $t[17]=5.92$, $P<0.001$; parent ratings, $t[21]=3.21$, $P<0.01$).

Pain frequency

When asked, "On average, how frequently do you experience pain", and given five forced choice response options, ranging from 'less than one-quarter of the time' to 'all of the time', the majority of children (77.8%, $n=14$) rated their recalled pretreatment pain frequency as 'all of the time', whereas only 38.9% ($n=7$) reported experiencing continuous pain after treatment. Similarly, the number of parents rating their child's pain as continuous after treatment versus recalled pretreatment pain frequency, also dropped by half, from 52.4% ($n=11$) to 23.8% ($n=5$).

Wilcoxon matched-pairs signed-ranks tests indicated significant decreases in pre- versus post-treatment pain frequency, according to both child and parent ratings (child ratings, $z[18]=-2.8$, $P<0.01$; parent ratings, $z[21]=-3.22$, $P<0.01$). There were no significant differences between children's and parents' ratings of recalled pretreatment ($z[15]=-1.72$, not significant) or current ($z[15]=-1.67$, not significant) pain frequency.

Degree of improvement in pain

On a more global rating, the majority of children (83.3%, $n=15$) and parents (95.2%, $n=20$) reported that their pain was at least 'somewhat better' (if not resolved) since completing treatment with the CPCS team. None felt that the pain was worse.

Treatment goals

Responses to the open-ended question, "When you were first seen by the CPCS, what did you hope to get out of treatment?", were coded, post hoc, into categories rationally derived to be qualitatively distinct. The most commonly reported treatment goals were to obtain total pain relief (38.9% of children, 42.9% parents), to learn ways to cope or deal with the pain (33.3% children, 47.6% parents) and to find a cause for the pain (5.6% children, 28.6% parents). Other less frequently reported categories of treatment goals included to learn about medications and to receive validation for the pain.

Attainment of goals

The majority of children (73.4%, $n=11$) and parents (76.2%, $n=16$) reported that their treatment goals had been at least partially achieved. The minority who felt that they had not reached their goals had as their sole treatment goal either 'total pain relief' or a clearly established cause for the pain (five of five of the parents, and three of four of the children).

Areas of improvement

Changes in pain management: When asked whether they "had noticed any changes in how the child deals or copes with pain since seeing the CPCS", 82.4% of children ($n=14$) and 85.7% of parents ($n=18$) spontaneously generated examples. The most common categories of changes reported were the use of specific cognitive-behavioural coping techniques (57.1% children, $n=8$; 42.1% parents, $n=8$); increased sense of control over the pain (28.6% children, $n=4$; 47.4% parents, $n=9$); and increased knowledge about their pain (28.6% of children, $n=4$; 15.8% parents, $n=3$).

Changes in 'areas other than pain': When asked whether they "had noticed any good or bad changes in areas other than the pain since coming to see the CPCS", 31.3% of children ($n=5$) and 47.6% of parents ($n=10$) generated responses. None of the participants reported 'bad' changes. The three most commonly reported positive changes were decreased emotional distress (60% children, 40% parents), increased self confidence (40% children, 30% parents) and a return to a 'normal' lifestyle (20% children, 40% parents).

Changes in participation in regular activities of daily living: Participants were asked, "Did the child's ability to participate in any of the following activities improve after seeing the CPCS: school attendance; homework; sleeping; eating; leisure activities; household chores; or family outings?". On average, children and parents endorsed improvements in four of the seven types of regular daily activities listed (children: mean 3.94, SD 2.65; parents: mean 3.95, SD 2.42). There were no significant differences between parent and child ratings of the number of areas improved ($t[14]=-1.06$, not significant).

Treatment satisfaction

When asked to rate, "How satisfied do you feel about the help that you and your child received from the CPCS?", using a scale where 0 = 'not at all satisfied', 1 = 'a little satisfied', 2 =

'quite satisfied' and 3 = 'extremely satisfied', the mean satisfaction rating for children was 2.17 (SD 0.62) and for parents was 2.24 (SD 0.77). A paired samples *t* test revealed no significant difference between parent and child satisfaction ratings.

Additional comments about outcome and treatment satisfaction

Some of the most powerful feedback about treatment satisfaction came in the qualitative form of comments that participants made in response to the final interview question – "Do you have any other comments regarding your experience with the CPCS?". Following are a few samples:

Meeting with the team was one of the most helpful things in all the years that I've been in pain. I think the team is great. It's nice to know they cared. I didn't need to repeat my history a bunch of times to each individual. They had lots of plans.

The doctor actually gave a crap about me!

The fact that the team believed her made all the difference.

DISCUSSION

The results of this retrospective interview study provide preliminary support for positive outcome and treatment satisfaction following interdisciplinary treatment of complex chronic pain in a pediatric sample. The perceived changes in pain and function following treatment by the CPCS were both statistically and clinically meaningful.

In this clinical sample of children and youths with previously recalcitrant complex pain syndromes and their parents, most reported ongoing pain. However, their interview responses indicated significantly lower post-treatment pain intensity levels and increased pain-free time, on average, in comparison with recalled pretreatment pain levels. They were also able to generate spontaneously examples of a variety of other areas of improvement, including adaptive coping with pain, mood and participation in regular activities of

daily living. The perceived changes described by this sample portray a picture of improved quality of life and a graduated return to healthy functioning following interdisciplinary treatment.

Given the design of this exploratory clinical study and the lack of control group, a causal relationship between changes and treatment by the CPCS cannot be scientifically confirmed, and the data are open to the potential biases of retrospective recall. Nonetheless, it is valuable to show that patients and parents seen in this interdisciplinary treatment program, who had not responded to previous treatments and who presented clinically as being highly dissatisfied with past health care, were so consistently positive in their ratings and descriptions of perceived changes associated with treatment and expressed such a high level of overall treatment satisfaction.

The finding that consistent improvements in pain levels were noted across different raters (child and parent) and across varying question formats (qualitative and quantitative) is supportive of the reliability and validity of the interview measure developed for this study.

The present qualitative data also provide some insights into expectations of patients and their parents when referred for treatment to an interdisciplinary pain service within an academic health care centre. Feedback about actual outcome may be valuable in helping future patients to set more realistic treatment goals.

This study is the first in an ongoing series evaluating treatment outcome among children, youths and parents seen by the CPCS. The present results will be strengthened by future studies that prospectively evaluate and compare pre- versus post-treatment pain and adjustment using standardized measures with known psychometric properties.

ACKNOWLEDGMENTS: We thank the families who participated in this study and acknowledge Kelly Giesbrecht for her assistance in categorizing the qualitative data. CT Chambers was supported by a doctoral award from the Medical Research Council of Canada.

REFERENCES

1. McGrath PJ, Finley GA. Chronic and recurrent pain in children and adolescents. *Prog Pain Res Manage* 1999;13:1-4.
2. Varni J, Rapoff M, Waldron S, Gragg R, Bernstein B, Lindsey C. Chronic pain and emotional distress in children and adolescents. *J Dev Behav Pediatr* 1996;17:154-61.
3. Bennett S, Huntsman E, Lilley C. Parent-perceived costs of complex chronic pain in children and adolescents. *Child Health Care* 2000;29:147-59.
4. Flor H, Fydrch T, Turk D. Efficacy of multidisciplinary pain treatment centres: A meta-analytic review. *Pain* 1992;49:221-30.
5. Berde CB, Masek BJ, Setha NF, Fosburg M, Rocklin S. Pediatric pain clinics: recommendations for their development. *Pediatrician* 1989;16:94-102.
6. Shapiro BS, Cohen DE, Covelman KW, Howe CJ, Scott S. Experience of an interdisciplinary pediatric pain service. *Pediatrics* 1991;88:1226-32.



Hindawi
Submit your manuscripts at
<http://www.hindawi.com>

