Pain Management Nursing 20 (2019) 245–252

Contents lists available at ScienceDirect

Pain Management Nursing

journal homepage: www.painmanagementnursing.org

Original Article

The Experience of Pain and Pain Tool Preferences of Hospitalized Youth

Elena M. Becker, BSN, RN, CPHQ [*], Bryan Wilson Jr., BSN, RN [*], Mei Lin Chen-Lim, MSN, RN, CCRC [*], Elizabeth Ely, PhD, RN [†]

[*] From the Children's Hospital of Philadelphia, Philadelphia, Pennsylvania
[†] University of Chicago Medicine, Chicago, Illinois

ARTICLE INFO

Article history:
Received 29 September 2017
Received in revised form
12 November 2018
Accepted 7 December 2018

ABSTRACT

Background: An accurate holistic pediatric pain assessment is necessary for quality pain management. Evidence continues to be published indicating inadequacies in pediatric pain management. It is important for clinicians to consider the pain assessment process while caring for youth.
Aim: The purpose of this study was to understand the pain experience through focused interviews and to explore how youth use, interpret and understand self-report pain assessment tools including their tool preferences.
Design: A qualitative descriptive study using a research developed semi-structured interview guide was conducted with 40 hospitalized youth, 10-17 years (M: 13yr; S.D. 2.4); 21 (52.5%) female on a medical inpatient unit. Interview questions focused on: current pain experience; pain related symptoms; evaluation of pain treatment and preferences for select pain assessment tools: 0-10 Numeric Rating Scale, The Oucher, Faces Pain Scale-Revised, and Adolescent Pediatric Pain Tool (APPT).
Setting: Large tertiary and quaternary care pediatric hospital located in northeastern United States.
Participants/Subjects: Hospitalized youth, 10-17 years of age.
Results: Analysis of transcribed interviews yielded 3 themes: My Pain Now, Pain Treatment Expectations, and Telling Healthcare Providers about My Pain. Additionally, pain tools preference, assessment frequency, and discussion of how behavior, activity level, and pain expression was different for each youth. APPT was the preferred pain assessment tool. Descriptive words such as sharp, throbbing, and aching were identified most often. Youth identified that activity and pain level often do not match.
Conclusions: Because pain is multi-dimensional, assessing each dimension (quality, location, intensity, and meaning) is key to thorough assessment. Results provide insight into youth preferences influencing clinical practice such as offering options for interventions and having a voice in the pain management process. All nurses caring for children should discuss available pain tools preferably before the child is in pain and assure the child knows how to use the tool.

Pain is one of the most misinterpreted and undertreated medical problems in pediatrics (Sng et al. 2017; Voepel-Lewis, 2011). Pain is a personal, subjective experience, and pain perception varies widely from one person to the next. An accurate, holistic assessment is necessary to ensure the management of pain, especially when evaluating effectiveness of interventions provided. Patient self-report of pain intensity (e.g., how much hurt/pain do you have?) is the most common measurement of pain used in clinical practice (Gagnon, Hadjistavropoulos, Hampton, & Stinson, 2016; Voepel-Lewis, Burke, Jeffreys, Malivya, & Tait, 2011). There are many types of pain tools available to obtain self-report. Even with the use of these tools, the information conveyed by the patient to the clinician can be misinterpreted or misleading. The patient who reports a pain score of 8 out of 10 but is then heard laughing with a friend on the phone or listening quietly to music may be perceived as having less pain than a score of "8" as perceived by the clinican assessing the patient. Is the challenge related to the patient's understanding of the use of the pain tool, or is it that the patient has developed coping mechanisms to alleviate some of the pain?

An accurate pain assessment is necessary to ensure the management of pain. Patient self-report of pain intensity (e.g., how

Address correspondence to Elena M. Becker, BSN, RN, CPHQ, Children's Hospital of Philadelphia, 3401 Civic Center Blvd, Philadelphia, PA 19104.
E-mail address: becker@email.chop.edu (E.M. Becker).

https://doi.org/10.1016/j.pmn.2018.12.003
1524-9042/

much pain/hurt do you have?) is the most common measurement of pain used in clinical practice (Baulch, 2010; Hicks, von Baeyer, Spafford, van Korlar, & Goodenough, 2001; Twycross, 2002). Recently the idea that self-report of pain intensity is the gold standard of pain assessment has been questioned (Berde & McGrath, 2009; Twycross, Voepel-Lewis, Vincent, Franck, & von Baeyer, 2015; Voepel-Lewis, 2011). Pain is a complex multidimensional symptom; therefore using a one-dimensional assessment may be inadequate. In the pediatric setting, pain assessment can be complicated by the child's age and developmental level. A number of reliable, valid tools are available to measure pain in children and are used regularly in clinical practice (Manocha & Taneja, 2016; Quinn, Sheldon, & Cooley, 2014; Stinson, Kavanaugh, Yamada, Gill, & Stevens, 2006). However, evidence continues to be published indicating inadequacies in pediatric pain management, such as parent/patient satisfaction <80%, analgesic medications not given when available, and clinician judgment superseding child-reported pain (Sng et al. 2017; Van Hulle Vincent and Gaddy, 2009). Therefore it is useful to consider how the process of pain assessment may be implicated in this problem. By clarifying the child's and adolescent's (youth's) report of pain and the clinician's assessment and understanding of the youth's pain, youths' overall satisfaction with pain management may improve. Literature supports that untreated pain has harmful physiologic and psychological long-term effects, which in turn directly affect a patient's overall tolerance of pain (Jordan-Marsh et al., 2004; Noel, Chambers, McGrath, Klein, & Stewart, 2012; Twycross, Forgeron, Chorne, Backman, & Finley, 2016). For example, a patient who has frequent exposure to needles may have a heightened response when interventions to prevent or manage pain are not implemented. Understanding how a patient interprets pain tools will help ensure a more accurate pain report, and therefore pain management will be more effective. If the clinician has a comprehensive understanding of the patient's pain, the clinician will be able to create an appropriate treatment plan and evaluate its effectiveness. This study focused on understanding the pediatric pain experience through semistructured interview questions and attention to the interpretation of the use of specific self-report pain tools by youth. By speaking directly to hospitalized youth, defined as children and adolescents, we can learn how they experience pain; how they wish to discuss it; and what methods they believe will help manage their pain (Franck, Sheikh, & Oulton, 2008; Sng et al., 2017).

Study Purpose/Aims

The primary objective of this study was to understand how hospitalized youth experience pain using focused interviews. The secondary objective was to explore how youth use, interpret, and understand selected self-report pain assessment tools, as well as learning effective pain interventions from their point of view.

Speaking directly with hospitalized youth regarding their thoughts, beliefs, and understanding of pain is extremely valuable. Adding their voice to the debate about best methods for pain assessment and management is key to more accurate and effective pain management.

Methods

Design

A qualitative, descriptive study design was conducted using a semistructured interview to explore youth pain experience. The interview questions were created based on the literature and the researchers' clinical and research experience related to pediatric pain. The questions were also pilot tested for clarity and understanding prior to data collection with youth hospitalized on the same study unit. The interview questions (Appendix A, Interview Guide) focused on four areas of a youth's pain experience: current pain experience, pain-related symptoms, evaluation of pain treatment, and preference of select pain assessment tools (Appendix B). Selected pain assessment tools were the 0-10 Numeric Rating Scale (NRS) (Voepel-Lewis et al., 2011), the Oucher (Beyer, Denyes, & Villarruel, 1992), the FACES Pain Scale—Revised (Hicks et al., 2001), and the Adolescent Pediatric Pain Tool (APPT) (Savedra, Holzemer, Tesler, & Wilkie, 1993). The pain assessment tools were selected based on age appropriateness, clinical utility, and strength of evidence for adequacy of reliability and validity (Stinson et al., 2006; Turk et al., 2006).

Setting and Sample

A convenience sample of 40 youth aged 10 to 17 years admitted to a large tertiary and quaternary care pediatric hospital located in northeastern United States was included in the study. Youth with developmental delay below the cognitive age of 10 years or with a history of a psychiatric diagnosis were excluded from study. Youth admitted to an inpatient medical unit specializing in hematology, rheumatology, and general pediatrics were primarily considered for study because of the convenient location for the interviewers. Youth were recruited by the three of the authors (E.B., B.W., and M.L.C.L.) and other members of the study team (Appendix C, Enrollment summary.). Youth were interviewed in their hospital rooms with preference of parents at bedside. The study was approved by the institutional review board, and written informed consent and assent was obtained before scheduling of the bedside interview. Youth were informed they had the option to stop at any time during the interview process.

Data Collection

Interviews were conducted by researchers E.B. or B.W. based on the interview guide and lasted 20 to 40 minutes. Interviews were recorded based on agreement from the youths and their parents or guardians. Thirty-eight youths and parents agreed for interviews to be recorded. Two youths and their respective parents declined recording but allowed field notes to be written during the interview. Recorded interviews were transcribed verbatim. Field notes were also collected along with the interviews. Transcripts and field notes were individually reviewed and coded by all authors during the qualitative analysis process.

Data Analysis

Both qualitative descriptive and qualitative content analysis were used to analyze the transcripts of all interviews to count specific content (e.g., words youths used to describe pain) and code like responses into categories and themes (Elo, Kääriäinen, Kanste, Pölkki, Utriainen, & Kyngäs, 2014; Ely, Chen-Lim, Carpenter, Wallhauser, & Friedlaender, 2016; Malterud, 2001; Sandelowski, 2000). First, researchers (E.B. and B.W.) who conducted the interviews reviewed the transcripts for completeness. Using qualitative descriptive methods, transcripts were coded independently by all research study authors, then shared as a group for discussion and comparison until consensus was reached. Second, all authors of the study recoded the transcripts using established codes and grouped like codes together to form categories representative of the coded content. During this step, exemplars (quotations/phrases) were identified from the transcripts by each researcher. Third, an independent round of analysis occurred using the agreed-upon categories, including a count of their occurrence in each transcript. Counts were compared and reconciled for any discrepancies.

Table 1
Themes and Categories With Examples

Theme: My Pain Now	
Detailed descriptors of pain (Fig. 1) • Youths able to use words and phrases to describe their pain *Type of pain (acute/chronic/episodic) (Table 3)* • Pain experience and history affected how youths described their pain as well as how they wanted to be asked about their pain *Why pain, not something else?* • Can be hard to separate pain from emotions for some	• No. 21: "Sharp, constant, kind of infuriating, irritating" • No. 12: "It felt like a huge punch" • No. 32: "Chest pain, can't breathe, felt like someone punching me in the chest, sharp" • No. 39: "It's like a sharp pain like someone's like poke…stabbing me and stuff" • No. 41: "Pain just feels different [from being nervous]" • No. 38: "I don't believe that being scared or nervous doesn't make pain worse"
Theme: Pain Treatment Expectations	
Where I want my pain to be • Personal goals for improvement; 12 (30%) reported desired goal of 0 out of 10 pain *Taking care of my pain: What works* • Ideas about what improves pain *What makes the pain worse?* • Stress/upset	• No. 17: "…Bearable"; no. 5: "No pain and walking"; No. 7: "From 7-8 down to 4"; No. 16: "Starts at 10, goes down to 5 and stay for 3-4 hours"; No. 21: "Quality of life should be normal"; No. 13, 15, 21, 34: "You always go home with a little bit of pain" • No. 9: "Walking around with like fresh air makes it better"; No. 40: "Heat makes it better; waiting it out" • No. 8: "Or if someone is saying I'm so sorry that hurts. That must be really painful…if they think it's so stress/upset then I guess it really must be painful. It doesn't help when people are like 'oh you poor thing'"; No. 12: [getting an intravenous line] "I think about it too much and then it hurts more…[so] I just distract myself by squeezing mom or dad's hand"
Theme: Telling Health Care Providers About My Pain	
How do you know about my pain? • Best tool: Review of pain assessment tools *How often to ask about my pain?* • Youths gave variable responses from 10 minutes after receiving the medication to every 3-4 hours *My behavior and level of activity does not always tell about my pain* • Actions and pain levels may not match. Do not assume; ask • Pain is different for every person	• No. 5 [APPT]: "This is a really good one because you get to color in first the parts that are in pain, and it explains; gets right to the point…how you feel in words…It has everything together"; No. 46: "You just can't really describe the pain in faces—people can react to pain differently" • No. 15: "I don't really mind them asking, I just want to get better"; No. 22: "Ask us to describe our pain"; No. 29: "Annoying when you are in pain and someone keeps asking you about it, reminds you of the pain" • No. 19: "I kinda push through the pain, I would keep going"; No. 8: "Just being active/having energy doesn't mean you are feeling fine"; No. 38: "[With less pain] probably I interact with people more, and if I was in pain I'd just be sitting here silent and probably sleeping" • No. 21: "Some people's pain tolerances are different. It's like when your worst pain ever could be a lot different than somebody else's"; No. 29: "Because your facial expression always doesn't show…I mean it doesn't always show how much the pain really feels because sometimes people try to tough it out and they don't make a face"

Finally, themes from categories were identified and discussed by authors. The analytic process used allowed researchers to remain true to the words and thoughts of youth interviewed. Coding came from direct words of the youth with categories created from similar codes (Table 1). Themes were developed by researcher consensus to represent overall data synthesis. Ongoing review of transcripts resulted in data saturation with the 40 youths.

Rigor

When conducting qualitative research, the rigor of the methodology differs from that of quantitative research because each has different theoretical underpinnings and standards (Sandelowski, 1986; Thomas & Magilvy, 2011). For example, rather than discussing reliability and validity of research instruments and data collection methods, the standards in qualitative research address the trustworthiness (credibility, consistency, confirmability, and transferability) of the process (Bernhofer, Hosler, & Karius, 2016; Creswell, 2012; Sandelowski, 1986; Thomas & Magilvy, 2011). Qualitative rigor was considered throughout the data collection and analysis process. Both interviewers (E.B. and B.W.) worked on the unit where the study was conducted. The fact that they were embedded in the unit as nursing staff was helpful in capturing thoughtful responses from youth interviewed because the youth had developed a rapport with and trust in the interviewers, lending support to the credibility of the collected data. Interview techniques and experiences were discussed in the early enrollment period during initial team meetings to ensure consistency between the interviewers, such as the use of open-ended questions to allow youth to discuss their experience more fully. Additionally, the discussions and review of transcripts during early enrollment allowed the more experienced researcher team members (B.E., M.L.C.L.) to coach and mentor the interviewers, further ensuring consistency. Interviews were transcribed verbatim and reviewed by interviewers to verify the transcribed data. Confirmability was established because analysis was started based on the youth's

Table 2
Demographic Characteristics

Demographic Characteristics (n = 40)	n (%)
Age, mean years (range, SD)	13 (10-17; SD 2.4)
Sex	
Female	21 (52.5)
Male	19 (47.5)
Race	
White	19 (47.5)
Black or African American	18 (45.0)
Asian	2 (5.0)
More than one race	1 (2.5)
Ethnicity	
Hispanic	2 (5.0)
Non-Hispanic	38 (95.0)
Diagnosis	
SCD pain/fever*	11 (27.5)
Asthma	5 (12.5)
Immunologic/rheumatologic	5 (12.5)
IBD (Crohn's/ulcerative colitis)	4 (10.0)
Aplastic anemia	3 (7.5)
General surgical	3 (7.5)
Migraine	2 (5.0)
Other	7 (17.5)

SD = standard deviation; SCD = sickle cell disease; IBD = inflammatory bowel disease.
* Includes ID 33 with SCD and asthma.

Table 3
Episodic vs. Acute Pain

Variables	Episodic Pain (Lives with Pain with Periods of Exacerbation) n = 25	Acute Pain (New Onset of Pain Episode) n = 15
Mean age, years	14	13
Gender		
Male	9 (36)	10 (66)
Female	16 (64)	5 (33)
What makes pain better?		
Pharmacologic	3 (12)	4 (26.6)
Nonpharmacologic	9 (36)	4 (26.6)
Both	12 (48)	6 (40.0)
Not asked	1 (4)	1 (4.0)
Feelings affect pain, Yes	15 (60)	9 (60)

transcripts. Once all researchers completed the individual coding process, each transcript was reviewed as a group, fostering a reflective dialogue to clarify individual researchers' interpretation of meaning and to minimize influence of individual beliefs or bias. Transparency of the analysis process and derivation of the themes are also representative of the data confirmability one of the standards of rigor in qualitative research.

Results

Demographic Characteristics

Our sample consisted of 40 youths aged 10 to 17 years (mean 13 years, standard deviation 2.4) hospitalized on a medical inpatient unit. Most of the youths were white (19, 47.5%) or black/African American (18, 45%) and female (21, 52.5%) and had diagnoses inclusive of the following: sickle cell disease pain/fever (11), asthma (5), immunologic/rheumatologic disease (5), inflammatory bowel disease (Crohn's/ulcerative colitis) (4), aplastic anemia (3), general surgery (3), migraine (2), and other (e.g., multiple diagnoses or none) (7) (Table 2, Demographic characteristics.). Based on diagnoses, youth were classified into episodic, chronic, or acute pain categories.

Episodic versus Acute Pain

Each youth had previous experience with pain. The majority (62.5%) had either chronic or episodic pain. *Chronic* or *episodic pain* refers to living with pain and periods of exacerbation throughout life, such as youths living with sickle cell disease or inflammatory bowel disease. *Acute pain* describes a new onset of a painful episode, which could be related to an injury, surgery, intravenous sticks, or injections. The type of pain experience among youth is delineated in Table 3. When asked if feelings affect pain, 60% of youth in each group stated that feelings do affect their pain. A thematic analysis of the interview transcripts with be discussed in the qualitative descriptive analysis section.

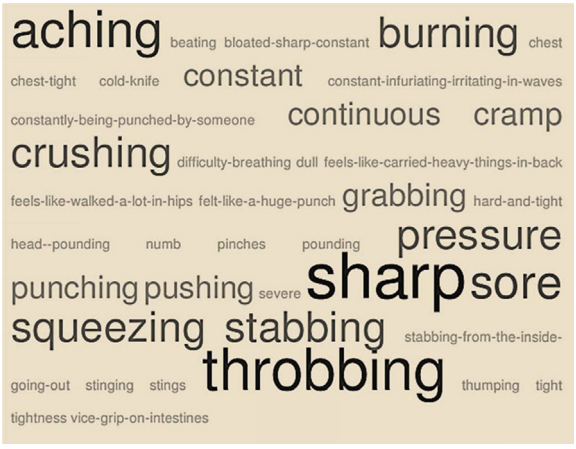

Figure 1. Descriptive words used by youths. All displayed words were used by participants to describe their pain. Words used more often are displayed more prominently (larger font or bolded) (From Steinbock, 2015).

Qualitative Descriptive Analysis

Interviews lasted on average for 14 minutes. Analysis of transcribed interviews yielded three themes: my pain now, pain treatment expectations, and telling health care providers about my pain (See Table 1 for complete themes and categories with examples.). Each of the themes are discussed next.

Qualitative Themes

My Pain now

My pain now encompassed three categories identified from the interview sessions. The categories were *detailed descriptors of pain, the type of pain,* and *how do we know this is pain and not something else. Detailed descriptors of pain* identified the youths' ability to use words and phrases to describe pain. Some examples are describe in a word cloud (Fig. 1) (Steinbock, 2015). The largest and boldest words in the word cloud are descriptive words that were stated more often by the youths, such as *aching, sharp,* and *throbbing.* Examples from the youth are as follows: “Tightness, gripping really hard” (ID no. 3) and “It's like a sharp pain like someone's like poke…stabbing me and stuff” (ID no. 39).

Type of pain was identified as acute or episodic/chronic (Table 3). Youths who had a history of episodic pain identified use of nonpharmacologic interventions, such as heat and distraction, more often than those who were experiencing acute pain. This was considered in relation to the youths’ responses.

Distinguishing between physical pain and feelings such as emotions that may feel like pain was discussed. Youth responded to this with the following comments: “Pain comes on more suddenly. A feeling that comes from the body.” (ID no. 24); “Pain is still there after anxiety meds/being tired or relaxed” (ID no. 27).

Along with the context of how feelings may or may not affect pain, youth were asked “Are there other feelings you are having that might affect pain?” Their responses varied as follows: “I know it is pain and not feelings because it's…it stopped me from doing a lot of things” (ID no. 29); “Fear, anxiety, nervousness makes it worse” (ID no. 31).

Pain Treatment Expectations

Pain treatment expectations were related to “where I want my pain to be” and the youth's personal goals for improvement, such as what works and what makes the pain worse. Youths reported goals for pain during treatment. Responses included the following: “Quality of life should be normal” (ID no. 21); “Starts at 10 goes down to 5 and stay for 3-4 hours” (ID no. 16). Twelve of the youths (30%) reported a desired goal of 0 out of 10 pain before discharge. Within the treatment expectations, youths identified internal and external factors: “It doesn't help when people are like ‘oh, you poor thing’“; regarding getting an intravenous line, “I think about it too much and then it hurts more…[so] I just distract myself by squeezing mom or dad's hand.” (ID no. 12); “I believe that if you have a bad mindset, it's going to seem worse than it is (ID no. 24). When asked “What works or helps you take care of the pain?” many youths responded “medications.” Additional identified

Table 4
Pain Assessment Tools: Helpful or Not Helpful to Explain Pain

Pain Assessment Tools	Helpful to Explain Pain	Not Helpful to Explain Pain
Adolescent Pediatric Pain Tool (APPT) (Fernandes, DeCampos, Batalha, Perdigão, and Jacob, 2014)	• Helpful and easy to use • Accurate method • More descriptive • Combination of pictures, numbers, and descriptive words • Accurate method to describe pain by providing a word bank to help put pain into words • Provides a lot more information about how the patient feels • Shows where the pain is located • Easy to target pain • Coloring part • Describes pain best • Good for patients with SCD and autism	• Complicated and complex • Too much information • Descriptive words could be confusing and some children may not know or understand all the words • Too extensive, involved, and time consuming • Found to be annoying to do repeatedly and difficult to complete when having pain • Worst pain scale • Too much to do
Oucher (Beyer, Denyes, and Villarruel, 1992; Beyer, Villarruel, and Denves, 2009)	• Realistic pictures are helpful in showing real emotion and pain and appear less cartoonish	• Pictures are out of order, creepy, not differentiated enough; faces appear sad versus being in pain and do not reflect the patient • Better for younger patients • Horizontal versus vertical does not make a difference • Not helpful and needs more of an explanation with pictures • Needs more pictures of faces • Never seen before
Numeric Rating Scale 0-10 (NRS) (Voepel-Lewis, Burke, Jefferys, Malviya, and Tait, 2011)	• Easy, simple, and to the point • Familiar • Used before without a physical visual scale • Can tell if pain worsened or improved • Best pain scale	• Not helpful and not accurate • Does not provide any information • No numbers present on the visual numeric scale, just slash marks • Numbers are undefined • Scale only tells one's pain amount/intensity and not descriptive • Range may vary from person to person • Worst pain scale • Uninvolved • Need more explanation when obtaining pain assessment
Faces Pain Scale—Revised (FPS-R) (Hicks, von Baeyer, Spafford, van Korlaar, and Goodenough, 2001; International Association for the Study of Pain, 2018)	• Can tell how someone feels by the facial expression example wrinkles on forehead increasing pain • Facial expressions are relatable and comparable • Visual representation of pain • Easy to use	• Faces appear sad, tired, sleepy, creepy, and cartoonish • One may be in a lot of pain but still not be crying; faces are not accurate; and some people may not experience same pain as shown (does not reflect the patient's actual face) • More faces needed • No explanation provided • Not differentiated enough

alleviators included the following: “Walking around with like fresh air makes it better” (ID no. 9); “Heat makes it better; waiting it out” (ID no. 40).

Telling the Health Care Providers About My Pain

For the theme *Telling the health care providers about my pain,* youths were asked to review pain tools and comment on “how do we know about your pain,” as well as the frequency with which to ask about the pain and how behavior affects the pain experience. Responses to pain tools included the following: “Cause it describes what you're feeling and the fact that you get to color where you're hurting so they can understand it better [APPT]” (ID no. 25); “You just can't really describe the pain in faces [FACES—Revised]—people can react to pain differently” (ID no. 46); “Little easier to describe [NRS]” (ID no. 17); “Shows real emotion [Oucher]” (ID no. 20). More information about how youths interpreted the tools during the interview process is given in Table 4. Specific interview questions with summaries of youth responses follow, helping elucidate the thoughtful and varied ideas these youths provided about their preferences.

For *“How often to ask about my pain?”* youths gave variable responses from 10 minutes to 1 hour after giving medication every 3-4 hours. Other specific comments included the following: “I don't really mind them asking, I just want to get better (ID no. 15); “When they ask what type of pain are you feeling maybe give us some choices” (ID no. 22); “Not so often, ‘cause sometimes it gets annoying, ‘cause when you're in pain and someone keeps asking you about it, reminds you of the pain” (ID no. 29); “Every hour and a half” (ID no. 45); “As often as CHOP currently asks and every few hours” (ID no. 42).

Regarding “*How does your behavior and level of activity reflect your pain?”* youths spoke about how activity level and behavior might not match what health care providers may consider to be pain. For example: “I kind of push through the pain, I would keep going” (ID no. 19); “Some kids react to pain in different ways, like they might look fine on the outside but on the inside they might be…in a lot of pain and stuff” (ID no. 39) “Just ‘cause you have energy doesn't mean you're feeling fine” (ID no. 8); “Because your facial expression always doesn't show…I mean it doesn't always show how much the pain really feels because sometimes people try to tough it out and they don't make a face” (ID no. 29); and “[With less pain] probably I interact with people more, and if I was in pain I'd just be sitting here silent and probably sleeping” (ID no. 38).

In regard to “*How can we know things are improving?*” another question youth considered thoughtfully was potential signs their pain was getting better. They said: “More activity means getting better” (ID no. 41, no. 39, no. 44); “Energetic, asking a lot of questions” (ID no. 26); “Moving and doing arts means improving” (ID no. 22); “Moving and talking and other things when feeling better” (ID no. 20); “Activity levels changes when getting better” (ID no. 2); and “Relaxing, up walking around” (ID no. 21). In addition to the

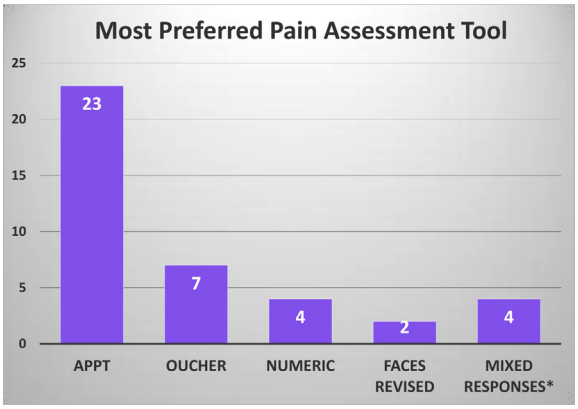

Figure 2. Most preferred pain assessment tool. *Mixed responses: ID 5 = preference not asked; ID 19 = mixed response between Numeric and APPT; ID 27 = preferred both APPT and Oucher. APPT = Adolescent Pediatric Pain Tool.

three themes identified when analyzing transcripts, content gathered from direct interview questions to all youths allowed us to quantitatively count responses such as words used to describe pain and which pain tools were preferred.

Qualitative Content Analysis

Pediatric patients are able to use descriptive words to explain their pain. A word cloud, as pictured in Figure 1, was created to highlight words used by youth to describe their pain. Words used more often are displayed more prominently in a larger font and bolded. The more commonly used words, such as *sharp, throbbing, aching, crushing, squeezing,* and *stabbing,* were expressed by many youths regardless of their age or pain experience. The word cloud represented all the descriptive responses provided by youths. As can be seen, some pain descriptors were used singly, where others were used more often.

Patients' Preference for Type of Pain Assessment Tool

In analyzing the responses to the question "Which scale do you prefer or like the most?" the most preferred pain tool identified was different among youths in the study, as shown in Figure 2. Overall the APPT tool was preferred by 23 of the 40 participants, whereas only 2 of the 40 youths preferred the FACES Pain Scale—Revised. In comparing the tools with one another, youths identified the APPT as having more components to describe pain; therefore it conveyed how they were feeling more accurately to the clinicians. The following comments were shared by youths to support their preference for the APPT tool: "I like all the words on the back, and the little scale 'cause they have all those pictures and…words. It has everything together" (ID no. 5); "Cause it shows like where your body hurts at and the feeling of it" (ID no. 4); "Tells how, where, why, and what the pain is" (ID no. 12); "Uses words to describe pain" (ID no. 1). The least preferred pain tool was the FACES—Revised. Youth commented that this tool did not accurately explain their pain. Comments included the following: "Cannot relate to faces" (ID no. 39); "Cause it looks a little crazy" (ID no. 31); "It doesn't really make sense" (ID no. 29).

Discussion

A patient's report of pain is much more than just a number. Throughout the interviews, youths willingly and articulately expressed their views on current and past pain experiences and pain management preferences. One youth stated that "some people's pain tolerances are different. It's like when your worst pain ever could be a lot different than somebody else's" (ID no. 21). Another youth said, "Don't judge a book by its cover" (ID no. 16). Youths responded that their own or others' actions and pain levels may not match, and clinicians should not make their own conclusion, but ask in a different way. In a recent study by Khadra et al. (2017) seeking to validate the psychometric properties of the 13-item Satisfaction of Adolescents with Postoperative Pain Management—Idiopathic Scoliosis scale, 82 adolescents rated the importance of each scale item along with their satisfaction with care related to those items. The item rated as highest in satisfaction and importance was "Believing you when you talk to them [nurses and doctors] about your pain." This item referred to the actions of clinicians in providing quality pain care and was scored on average at 5.0 ± 1.2 for satisfaction and 5.5 ± 0.8 for importance on a 6-point scale with 6 as very satisfied/very important. Youths in this study highly valued the perception that the clinicians believed them when they discussed their level of pain.

Pain experience and history affected how youths described their pain as well as how they wanted to be asked about their pain. Youths, depending on their experience, differentiated pain versus another symptom. Youths with less experience stated they could not always separate emotions from pain.

During the interview, youths used several descriptive words to explain their pain. Youths provided both positive and negative feedback on four validated pain assessment tools presented to them during the interview. Most of the participants preferred the APPT as most effective pain assessment tool in communicating their report of pain. Evaluation of the pain tools by the youths elicited positive and negative aspects of each tool, as listed in Table 4. The APPT was described as a helpful and detailed method to express pain. The youths stated the combination of a body outline drawing, numeric rating scale, and descriptive words helped them explain current pain most accurately. The combination of the three sections of this tool enhanced the perspective of the youths' ability to explain their current pain. A measure of pain intensity alone was insufficient. Negative responses included that this tool was more complex and time consuming when a youth is experiencing pain. The Oucher was found to be helpful because the pictures appeared realistic, showing real emotion and pain and not cartoon figures. The older youths perceived that this tool might be better for younger patients. Negative feedback was that pictures were not differentiated enough in the intensity of pain. The NRS was easy and familiar as a positive response, but participants commented that the numbers were undefined and the meaning of a number (0-10) may vary by person. Regarding the FACES Pain Scale—Revised, participants acknowledged that the facial expressions were relatable and that the increase of wrinkles appearing on the faces portrayed increasing pain. Negative factors were that the faces appeared sad, tired, sleepy, and creepy.

Pain is subjective, and everyone's view on pain differs from person to person. By completing a thorough pain assessment, the clinician can develop an individualized care plan with interventions to effectively address and manage a child's pain. Clinicians need to have a conversation with their patients about their report of pain, asking youths questions such as "When you tell us you have pain and we try to decrease the pain (e.g., using medicine, change your position, etc.), how can we know things are improving, staying the same, or getting worse?", "What level/amount of improvement in your pain do you want to have?" and "Can we understand improvement in your pain based on your ability to walk, sleep, or do the things you like to do?" This study

supports communicating with and listening to our patients to gain insights, ideas, and personal perspectives about how best to manage their pain. There are multiple evidence-based pain assessment tools available to help guide and facilitate the conversation at the bedside regarding a patient's report on pain. It is imperative to make sure youths understand the tool and how to use it effectively.

Youths also had concrete ideas about how to help manage their pain when asked. Similarly, in a study by Franck et al. (2008) of 71 children and adolescents (mean age 9.25 ± 3.04 years) asked to write about and draw their pain experiences, each youth identified the desire to be an active agent in his or her pain relief. The youths in the Franck et al. (2008) study also had specific ideas for interventions, such as active distraction techniques and helping decide when pain medications were needed.

Limitations

Qualitative rigor was limited by the fact that youths were not available to review qualitative findings (Malterud, 2001; Sandelowski, 2000). Pediatric pain assessment tools evaluated by youths were chosen from a group of validated tools and not inclusive of all tools available (Stinson et al., 2006). The choice to include two FACES-type tools, the commonly used NRS and the APPT, was made to include the “usual” tools of pain intensity often introduced in clinical practice but also to provide a more multidimensional tool. Pain is defined as subjective and multidimensional, but in clinical practice, time often limits pain assessment to a one-dimensional tool.

Implications for Practice

Information received during the interview process provides the clinician with an understanding of the pain experience in the pediatric patient population. Pain is multidimensional and personal to the individual patient no matter his or her age or background. The preferred pain assessment tool differs among patients in this group by age and exposure to previous pain tools or pain experience. Hospitalized youth are able to use descriptive words to explain pain. Asking the patient for more than just a number on a tool or pointing to a picture is important because descriptive information can provide the clinician with additional information to best develop a pain management plan with the youth. The clinician must discuss available pain tools, explain how to use the tool, and make sure the youth knows how to use it, allowing the youth to decide which tool best describes his or her pain. Additionally, partnering with youths to discuss the plan of care, ensuring their input about intervention choices, is imperative. As clinicians, we are responsible for ensuring that patients’ voices are clearly reflected in their care plan.

Conclusions

Experiencing pain is the basis for many youths to seek treatment and care. Conducting a thorough pain assessment is the initial step to providing effective pain management. Obtaining pain assessment from the youths' perspective has demonstrated that they can and should be partners in their pain management. Regardless of age and experience, youths are capable of expressing their pain more descriptively but require more than a one-dimensional assessment. Thus pain tools can help initiate this conversation and improve understanding of a youth's experience of pain. The children and adolescents in this study expressed their desire to actively contribute to their pain management. Overall, our experience is that youths would like to actively contribute to their pain management, and they have indicated that they can. With more understanding and trust, clinicians can partner with patients to provide better care for pain.

Supplementary Data

Supplementary data related to this article can be found online at https://doi.org/10.1016/j.pmn.2018.12.003.

References

Baulch, I. (2010). Assessment and management of pain in the paediatric patient. *Nursing Standard, 25*(10), 35–40.

Berde, C., & McGrath, P. (2009). Pain measurement and beecher's challenge: 50 years later. *Anesthesiology, 111*, 473–474.

Bernhofer, E. I., Hosler, R., & Karius, D. (2016). Nurses' written responses to pain management values education: A content analysis. *Pain Management Nursing, 17*(6), 384–391.

Beyer, J., Denyes, M., & Villarruel, A. (1992). The creation, validation, and continuing development of the oucher: A measure of pain intensity in children. *Journal of Pediatric Nursing, 7*(5), 335–346.

Beyer, J. E., Villarruel, A. M., & Denyes, M. J. (2009). The Oucher: User's manual and technical report. Retrieved from http://www.oucher.org/downloads/2009_Users_Manual.pdf. (Accessed 28 April 2014).

Creswell, J. W. (2012). *Qualitative inquiry and research design: Choosing among five approaches*. Los Angeles, CA: SAGE.

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). Qualitative content analysis. *SAGE Open, 4*(1), 1–10.

Ely, B., Chen-Lim, M. L., Carpenter, K., Wallhauser, E., & Friedlaender, E. (2016). Pain assessment of children with autism spectrum disorders. *Journal of Developmental and Behavioral Pediatrics, 37*(1), 53–61.

Fernandes, A. M., DeCampos, C., Batalha, L., Perdigão, A., & Jacob, E. (2014). Pain assessment using the adolescent pediatric pain tool: A systematic review. *Pain Research Management, 19*(4), 212–218.

Franck, L., Sheikh, A., & Oulton, K. (2008). What helps when it hurts: Children's views on pain relief? *Child: Care, Health and Development, 34*(4), 430–438.

Gagnon, M. M., Hadjistavropoulos, T., Hampton, A. J. D., & Stinson, J. (2016). A systematic review of knowledge translation (KT) in pediatric pain: Focus on health care providers. *Clinical Journal of Pain, 32*(11), 972–990.

Hicks, C., von Baeyer, C., Spafford, P., van Korlaar, I., & Goodenough, B. (2001). The Faces Pain Scale–revised: Toward a common metric in pediatric pain measurement. *Pain, 93*, 173–183.

International Association for the Study of Pain. (2018). Faces pain scale–revised. Retrieved from www.iasp-pain.org/FPSR. (Accessed 28 April 2014).

Jordan-Marsh, M., Hubbard, J., Watson, R., Hall, R. D., Miller, P., & Mohan, O. (2004). The social ecology of changing pain management: Do I have to cry? *Journal of Pediatric Nursing, 19*(3), 193–203.

Khadra, C., Le May, S., Ballard, A., Therouz, J., Charette, S., Villeneuve, E., Parent, S., Tsimicalis, A., & Chorney, J. M. (2017). Validation of the scale on satisfaction of adolescents with postoperative pain management—idiopathic Scoliosis (SAP-S). *Journal of Pain Research, 10*, 137–143.

Malterud, K. (2001). Qualitative research: Standards, challenges and guidelines. *Lancet, 358*, 483–488.

Manocha, S., & Taneja, N. (2016). Assessment of paediatric pain: A critical review. *Journal of Basic and Clinical Physiology and Pharmacology, 27*(4), 323–331.

Noel, M., Chambers, C. T., McGrath, P. J., Klein, R. M., & Stewart, S. H. (2012). The role of state anxiety in children's memories for pain. *Journal of Pediatric Psychology, 37*(5), 567–579.

Quinn, B. L., Sheldon, L. K., & Cooley, M. E. (2014). Pediatric pain assessment by drawn faces scales: A review. *Journal of Pain Management Nursing, 15*(4), 909–918.

Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science, 8*(3), 27–37.

Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description? *Research in Nursing and Health, 23*, 334–340.

Savedra, M. C., Holzemer, W. L., Tesler, M. D., & Wilkie, D. J. (1993). Assessment of postoperation pain in children and adolescents using the adolescent pediatric pain tool. *Nursing Research, 42*(1), 5–9.

Sng, Q. W., He, H.-G., Wang, W., Taylor, B., Chow, A., Klainin-Yobas, P., & Zhu, L. (2017). A meta-synthesis of children's experiences of postoperative pain management. *Worldviews on Evidence-Based Nursing, 14*(1), 46–54.

Steinbock, D. (2015). TagCrowd. Retrieved from https://tagcrowd.com/. (Accessed 30 November 2016).

Stinson, J. N., Kavanaugh, T., Yamada, J., Gill, N., & Stevens, B. (2006). Systematic review of the psychometric properties, interpretability and feasibility of self-report pain intensity measures for use in clinical trials in children and adolescents. *Pain, 125*, 143–157.

Thomas, E., & Magilvy, J. K. (2011). Qualitative rigor or research validity in qualitative research. *Journal for Specialists in Pediatric Nursing, 16*(2), 151–155.

Turk, D. C., Dworkin, R. H., Burke, L. B., Gershon, R., Rothman, M., Scott, J., & Cowan, P. (2006). Initiative on methods, measurement and pain assessment in clinical trials. Developing patient-reported outcome measures for pain clinical trials: IMMPACT recommendations. *Pain, 125*(3), 208–215.

Twycross, A. (2002). Educating nurses about pain management: The way forward. *Journal of Clinical Nursing, 11*(6), 705–714.

Twycross, A., Forgeron, P., Chorne, J., Backman, C., & Finley, G. A. (2016). Pain as a neglected patient safety concern: Five years on. *Journal of Child Health Care, 20*(4), 537–541.

Twycross, A., Voepel-Lewis, T., Vincent, C., Franck, L., & von Baeyer, C. L. (2015). A debate on the proposition the self-report is the gold standard in assessment of pediatric pain intensity. *Clinical Journal of Pain, 31*(8), 707–712.

Van Hulle Vincent, C., & Gaddy, E. J. (2009). Pediatric nurses' thinking in response to vignettes on administering analgesics. *Research in Nursing and Health, 32*, 530–539.

Voepel-Lewis, T. (2011). Pain assessment and decisions making: Have we missed the mark? *Pediatric Pain Letter, 13*(1), 1–6.

Voepel-Lewis, T., Burke, C. N., Jeffreys, N., Malviya, S., & Tait, A. R. (2011). Do 0-10 numeric rating scores translate into clinically-meaningful pain measures for children? *Anesthesia and Analgesia, 112*, 415–421.