

Participant-Generated Timelines: A Participatory Tool to Explore Young People With Chronic Pain and Parents' Narratives of Their Healthcare Experiences

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Abstract

Visual methods are becoming more evident in health research. Timeline drawings have been used as a participatory tool alongside interviews in life course research. In this article, we describe how a method involving timeline generation can explore patient experiences along a treatment continuum. Grounded in previously published evidence and using specific examples from two studies exploring the experiences of young people treated for chronic pain, we outline the key components of this method. Moreover, we highlight the flexibility of its application and the importance of using a person-centered approach in tailoring the application pragmatically to study population-specific needs and characteristics, while answering the research question. We also reflect on how the dynamic visual display of the timeline and participants' explanations add perspective and understanding to complex and multidimensional human experiences associated with healthcare treatment. Furthermore, we outline how this method can help capture changes in the meaning and sense-making of these experiences over time, all the while fostering empowerment in study participants. Finally, the key considerations of using the method are outlined. It is our aim that this article provides the details required to inspire others to consider this novel method as a means of capturing the healthcare experiences of young people with other chronic conditions, an important first step in fostering the changes required to improve the quality of healthcare services and research.

Keywords

timelines, visual methods, participatory approaches, young people with chronic pain

Background

Since the United Nations Convention on the Rights of the Child, emphasis has been placed on the participation of young people in research (Coad, 2007; Haijes & van Thiel, 2016). Increased participation of young people has been seen in social science studies; however, the healthcare field has lagged (Haijes & van Thiel, 2016). Qualitative research has often privileged language-based data collection strategies (Bagnoli, 2009). Alongside an increased interest in engaging more vulnerable and underrepresented populations, a shift toward inclusive methods occurred (Wheeldon & Faubert, 2009); however, managing power relations has proven challenging (Kolar & Ahmad, 2017; Kolar et al., 2015; Melvin et al., 2022; Pfister et al., 2014). Visual methods are a highly versatile

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way of capturing a more nuanced depiction of lived experiences, while at the same time empowering study participants (Literat, 2013).

Visual methods comprise a variety of media, from already-created images (e.g., magazine photos) and visual objects (e.g., artifacts) to the use of participant-generated imagery (i.e., images created by study participants) (Foster, 2016). To date, minimal literature exists on how to use participant-generated imagery to guide and supplement semi-structured interviews within health science disciplines specifically, when exploring a young person's and their caregiver's experiences with health treatment services related to a specific condition from a temporal perspective.

Young people experiencing chronic pain have been identified as a vulnerable population, for whom creative approaches are required to elicit their underrepresented views and opinions about their healthcare and their experiences related to the treatment services received (Caes & Jordan, 2017). Up to 38% of young people experience persistent or recurrent pain lasting 3 months, meeting the diagnostic criteria of chronic pain (Aydede, 2017; King et al., 2011). In comparison to their peers, this clinical population has higher anxiety scores, higher rates of depression (Eccleston et al., 2004), higher post-traumatic stress disorder symptoms (Noel et al., 2016), and reduced contact with friends and the public (Forgeron et al., 2010). Interviews are reported to elicit anxiety as participants reflect and share traumatic and difficult experiences (Hoolway & Jefferson, 1997) and raise concerns regarding potential exploitive relationships (Holland, 2007; Nicholls, 2009).

Timeline drawings are a visual art-based method, derived from a broader framework of graphic elicitation (Bagnoli, 2009; Sheridan et al., 2011). They are created from participants' life events, ordered in a self-selected chronology, with meaning attached to the events identified (Berends, 2011). The timeline method can help reduce the traditional hierarchies of interviews, encouraging rapport building between the interviewer and interviewee, and allowing the participant (and not the interviewer) to navigate the interview agenda (Kolar et al., 2015). Moreover, timelines can also help participants reflect on specific periods of their lives (Pfister et al., 2014) and like other visual methods (e.g., photo voice) can enrich the comprehensive understanding of a participant's own experience (Noyek et al., 2022).

Drawing from the field of social sciences, this article will discuss the use of visual methods as an adjunct to language-based methods, such as semi-structured interviews, to explore the multidimensional and complex human experience of chronic pain and its treatment in healthcare service research involving young people and their parents. Reflecting on two case examples, using

existing literature for support and sharing exemplar timelines and quotes from the cases, this article aims to (i) illustrate the application and flexibility of the timeline method and (ii) provide scaffolding for using timelines as a method for collecting and constructing narratives of young people with chronic pain, and their parents, about their healthcare treatment experiences. Key considerations, reflections, and guidance for using this visual method with young people and parent interviews are identified. It is our hope that this article helps lay the groundwork for other researchers to conduct studies exploring the experiences of young people with other chronic conditions with healthcare treatment.

Setting the Scene

In the cases described in this article, the integration of timelines into the interview process emerged as a way to better understand the experiences of young people with chronic pain and their parents in receiving healthcare treatment for their condition. In contrast to the literature where timelines are used to explore a participant's whole life course, the cases focused on a specific period of time when a young person and their parent had engaged with healthcare treatment. Moreover, the intention for using the timeline method was not for therapeutic purposes, but instead to gather information about young people's and parents' treatment experiences to guide future treatment improvements (Monico et al., 2020). The term young person is used throughout the article to describe older or more experienced children who are more likely to be able to make decisions for themselves (General Medical Council, 2012). It was the term preferred by the young people participating in the described cases. To add context to the considerations, reflections, and guidance shared in this article, a brief description of each case is provided. More details about each study have been published separately elsewhere (Hurtubise et al., 2021; Joslin et al., 2021, 2023).

Study Examples

Case 1 was informed by Q methodology (Brown, 1993) and integrated timelines within semi-structured interviews to establish which outcomes young people (aged 11–18 years old) and their parents considered important to measure during the treatment of chronic pain. The aims were to develop a set of statements (Q set) from the words and statements of young people and parents that reflected important outcomes of treatment and to explore whether their opinions change over the course of treatment. Following ethical approval from the National Health Service (NHS, Leeds, UK) Research Ethics Committee (Ref: 18/SC/0138), a purposive sample of young people ($n = 21$)

and parents ($n = 21$) was recruited between May 2018 and April 2019 from physiotherapy, rheumatology, psychology, and pain services across two hospital sites in England. Where possible, young people and parents were interviewed separately and could choose to be interviewed either face-to-face (in a hospital or home setting), via the telephone, or using online methods (instant messaging or video call).

Case 2, the third phase of a participatory evaluation study, used an interpretive descriptive design (Thorne, 2016) and employed timelines within the semi-structured interview process. This study aimed to identify, describe, and compare the effects and impacts of two different chronic pain interventions as experienced by young people (aged 12–18 years) with chronic pain and their parents. Following ethical approval received from the Co-Joint Health Research Ethics Board, University of Calgary (Ref: REB16-0916), and Research Ethics Board of the Centre intégré de santé et des services sociaux de l'Estrie—Centre hospitalier universitaire de Sherbrooke (Ref. 2017-1543), a purposeful sample of young people ($n = 14$) and parents ($n = 10$) was recruited between December 2017 and April 2019 through pain clinics (i.e., complex pain and headache) and two specialized chronic pain intervention programs at the same hospital in Western Canada. Parents and young people were interviewed separately, in the context of their choice (i.e., the hospital or at home) and using their preferred medium (i.e., in-person, telephone, or video call).

It should be highlighted that the research cases presented were conducted separately in different countries before we, the authors, became aware of our common interest in the use of timelines. As physiotherapists, we share a world view of pragmatism; our research has a real-world orientation, explores what matters to young people and parents, and focuses on methods that can be applied in real-life clinical contexts (Creswell & Plano Clark, 2011). The decision to integrate timelines as a supplementary method of gathering data alongside participant interviews was informed by young people experiencing chronic pain and their parents during the study design phase of each study. Placing the young person and their parent at the center of the research design process, a concept reflected throughout this article, gave rise to a list of key considerations when integrating timelines into our study design.

Key Considerations

When integrating timelines into a study involving young people and their parents, the following four considerations warrant careful thought: (1) timelines are person-centered; (2) combining visual and language-based communication helps improve understanding; (3) creating a timeline empowers the participant; and (4) timelines are temporal,

capturing change over time. Figure 1 provides an illustration of the relationship between the considerations. Each consideration will be described using existing literature and data (i.e., timelines and quotes) from the aforementioned studies.

The Rationale: Timelines Are Person-Centered. As clinicians working with this clinical population, we were aware of the potential challenges of this vulnerable group and wanted to ensure the methods used best captured their voices. Advice sought from a subset of young people experiencing chronic pain and their parents early in the research process highlighted the importance of non-verbal visual methods to communicate their complex experiences confidentially and to express their relativity to other life events. This consultation resulted in the decision to include timeline drawings within the interview process.

In Case 1, patient and public involvement and engagement were sought during the design phase from eleven young people being treated for chronic pain and three parents. The young people expressed varied opinions on their preferred method of communication. Seven of the young people discussed a general dislike of talking to others, especially those they had not met before. Two of the young people expressed they would be unable to talk out loud and would require a method of written or online text communication. The reasons given included social anxiety and fear of being overheard when confidentiality could be compromised (e.g., in the family home where others were present). Drawing and writing on the timeline provided a mechanism to express something without talking out loud, reducing the fear of being overheard by a family member. To assess the acceptability of using a timeline with this clinical population, two female patient representatives (11 and 16 years old) developed and tested the timeline activity. Using the instructions from the *Save the Children Norway (2008)* toolkit for participatory research, these two patients constructed their own timelines, completing the activity without difficulty; and natural conversation resulted during the process. In collaboration with the researcher, they assisted in rephrasing and simplifying the instructions and creating an interview schedule.

In Case 2, a study advisory committee composed of clinicians, a physician, a healthcare administrator, and young people with chronic pain and their parents selected the timeline method from other art-based options. All members agreed that understanding the relativity of the pain experience across time and within the context of the young person's and family's life was vital to answering the research question. The use of a timeline allowed for this to be achieved, providing a structure for ordering experiences and ideas and facilitating communication between the interviewer and interviewee

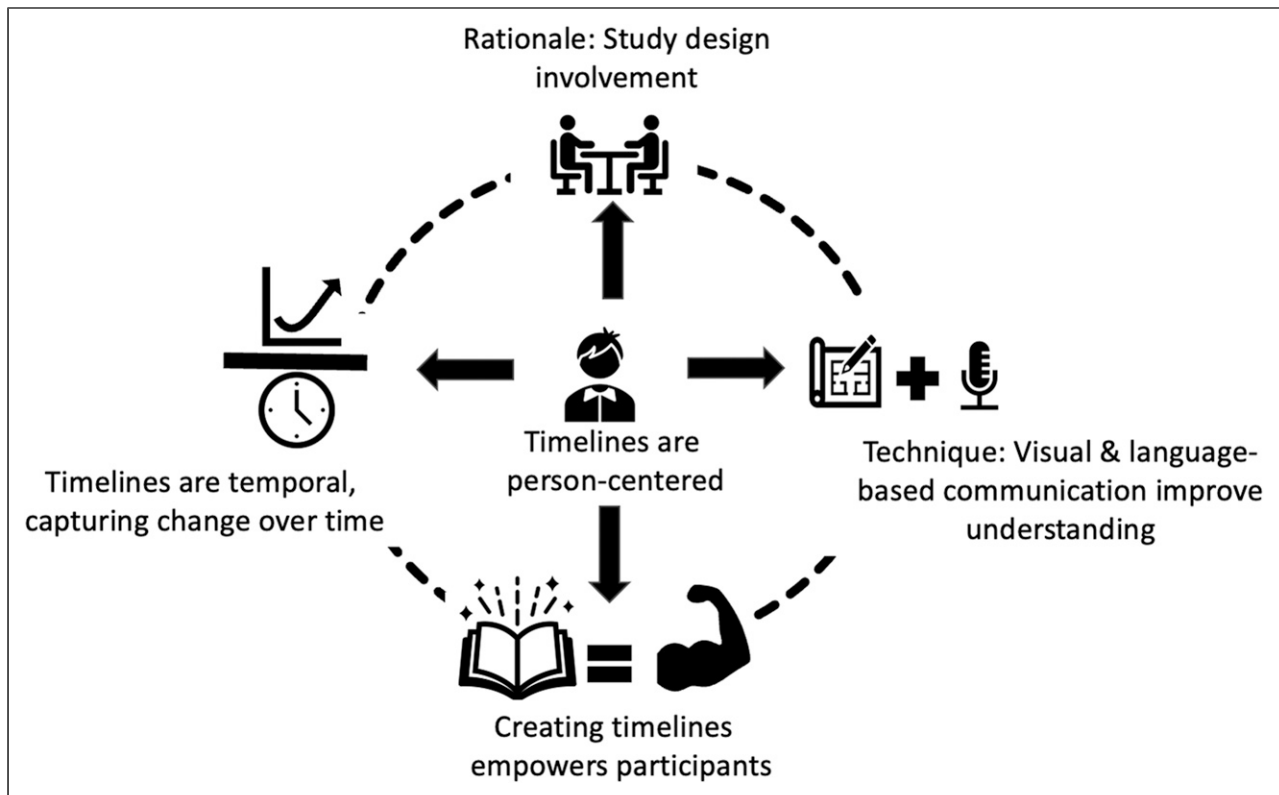


Figure 1. Summary of the key considerations.

(Monico et al., 2020; Nickerson et al., 2013). Furthermore, young people and parent advisory committee members recognized that some participants may be resistant to and/or not confident in their ability to complete art-based activities, a known limitation of visual methods (Scherer, 2016). Drawing, sculpting, and taking photographs to their satisfaction were identified as potentially anxiety-provoking and risked exacerbating participants' symptoms (Nickerson et al., 2013). Once the method was selected, young people and parent advisory committee members piloted the timeline interview process, and like Case 1, the participant instructions on how to create a timeline and the timing of the timeline creation in relation to the interview were modified as a direct consequence of their feedback.

The Technique: Combining Visual and Language-Based Communication Improves Understanding. The application of the timeline is not complicated. Just as interview questions are carefully adapted to participants, the timeline technique can also be modified (Sheridan et al., 2011). In both studies, participants were reassured that timelines did not have to be completed in any specific way and should be considered a "doodle" of what was going to be or was being talked about. Additionally, participants selected the location and through what medium the

interview was conducted (e.g., in-person at the hospital or at their home, over the telephone, via video platform or instant messenger).

Completion of the timeline requires basic materials, such as a piece of paper, pencils/pens, and multiple-colored markers. These tools provide participants with as much or as little creativity as they deem necessary (Adrianson, 2012; Gramling & Carr, 2004). Two distinct timeline styles have been reported: continuous-line timelines (see Figures 2, 4 and 5) and list-like (see Figure 3) timelines (Kolar et al., 2015). Most publications describe the continuous-line timeline style, where a line is drawn in the middle of the page, either horizontally, vertically, or wavy (Adrianson, 2012). The line orientation can vary depending on the interviewee's preferences and reflects the participant's perceptions of the significant events in their journey (Adrianson, 2012; Leung, 2010; Wainer & Velleman, 2000). Most importantly, a clear beginning and end should be evident (Adrianson, 2012). List-like timelines are reported to be more text-heavy, consist of one or more columns with short phrases or keywords, and may or may not include dates (e.g., years, months, and school grades) (Kolar et al., 2015).

With both the line and list timeline approaches, dots, dashes, Xs, symbols, and adjunct materials such as

stickers or magazine clippings may be used by the participant to add further meaning (Kolar et al., 2015). In Case 1, a “+” was used by some participants to indicate a positive treatment outcome and a “-” if it was negative. Alternatively, in Case 2, “happy faces” were used by a parent participant to identify time periods when her daughter’s pain was well controlled and things were going well and “sad faces” when things were “spiralling downwards, out of control, or when the pain was unmanageable.”

In Case 1, contrary to previous findings (i.e., Kolar et al., 2015), where list-like timelines were used by young people more than adults, only one parent wrote a list-like timeline; all young people ($n = 21$) and the remaining parents ($n = 19$) drew a continuous-line timeline in a horizontal orientation. Most of the lines were wavy (10 parents and 16 young people) versus a straight line (9 parents and 5 young people). The timeline template consisted of two circles, alongside a person symbol and the words “start” and “end” of treatment at either end of a horizontally oriented A4 piece of paper (Figure 2). While not intentional, the timeline template and the instruction “now join the dots in a way to show your treatment so far (and how it will look into the future)” appear to have facilitated this wavy continuous-line format.

Alternatively, in Case 2, participants were asked to draw a timeline without any pre-set templates. The timeframe used was determined by the participants themselves as per protocols used in previous research (Bagnoli, 2009; Sheridan et al., 2011). Encouragement was given to focus on the period in their lives when pain (or their young person’s pain) was a concern. Timelines adopted various formats: 10 participants created vertical list-like timelines (see Figure 3), while 12 generated a horizontal continuous line (see Figure 5). In contrast to the literature, both continuous-line and list-like timelines were text-heavy and detailed. Interestingly, parent and young person dyads used the same format, even though timelines were created independently.

The freedom to create the timeline in a way that represented their personal journey through treatment was pivotal in both cases. In Case 1, U-turns were drawn by both young people and parents. Young people named these U-turns “turning points,” and they inspired a final theme. The accuracy of the ups and downs was important to participants; as seen in the bottom left corner of Figure 2, the young person redrew the line to ensure clarity. Similarly, in a study by Looman and colleagues (2022), which explored young people’s perception of quality of life, “turning points” were described as rebound

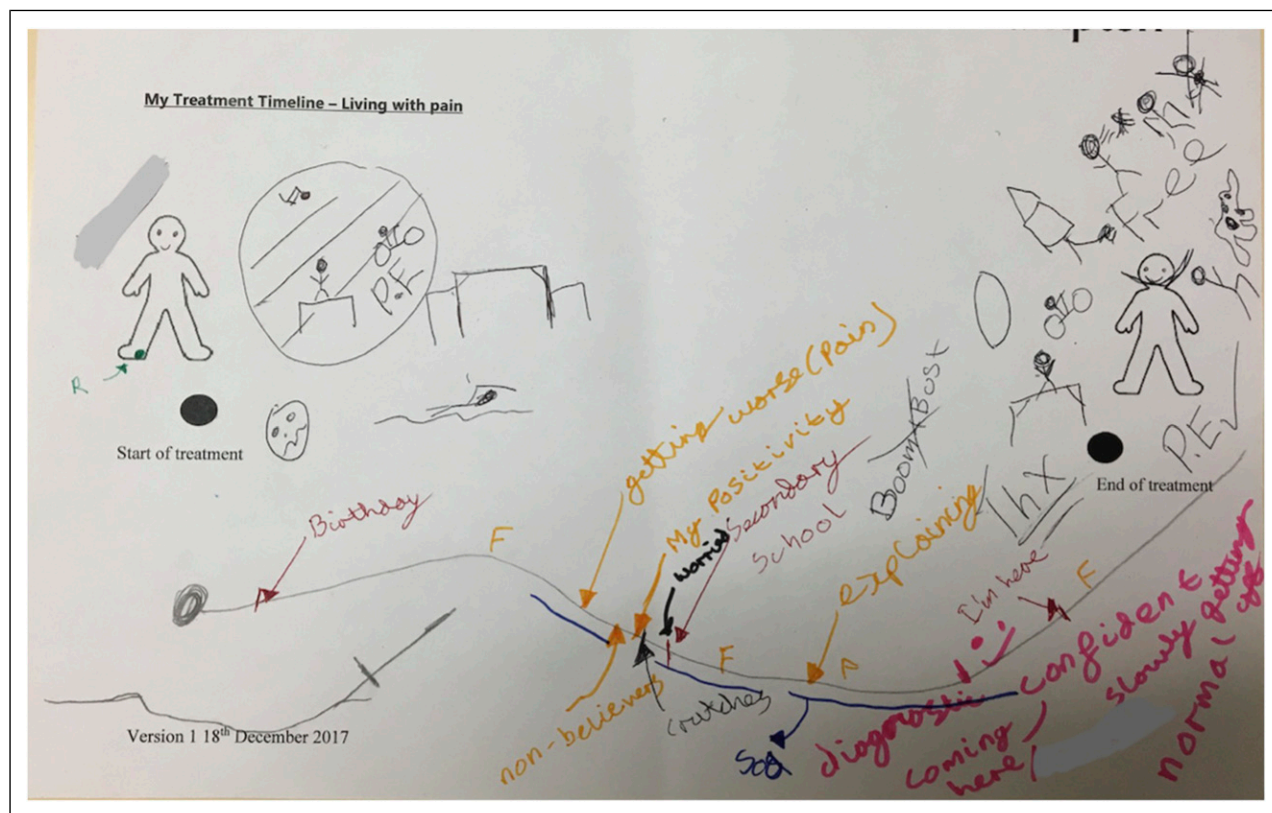


Figure 2. Example list-like timeline created by a young person in Case 2.

INSTRUCTIONS: Please draw a timeline of your life up until now and mark the most important events and the changes that have happened.

Grade 9- Winning zones, but a cracked rib in that basketball season.

Grade 10- Played one basketball game, felt a huge pain in my chest. Referred to chronic pain clinic.

Grade 11- Travelled to Europe, I IPT ██████████. Diagnosed with Ehlers Danlos Syndrome.

██████████ - Major fallout with best friend, met in I IPT

██████████. Decisions about changing a program.

██████████ - Came out to parents, asked out first girlfriend.

██████████' - Moving ██████████, new program.

Figure 3. Example from Case 1 of a young person using layers along the timeline.

points and were drawn by 48.7% of the 448 young people as a low point followed by a sharp rise (rebound point) on their timeline.

The timeline can be created solely by the individual or co-constructed with the researcher (Adrianson, 2012). Participants in Case 1 individually created their timelines during a single interview. In Case 2, the timeline was co-constructed, with the interviewer adding events, with the participant's permission during the interview, using a different colored pen. This provided a means of paraphrasing, adding new events uncovered in the interview, which lead to mutual understanding of the experiences.

As suggested by Adrianson (2012, p. 43), "the backbone of this method is the drawing of the timeline." The linearity of a timeline has often been highlighted as a weakness of this approach (Monico et al., 2020); this was not experienced in our studies. As shown in Figure 4, participants using a straight line added layers in different colors to create meaning and understanding. These layers were interconnected to show overlap using labels such as "start of school, low mood" having the layers "school stress," "doctors a lot," and "other pain" above.

During the interview, the participants were encouraged to add new events or information emerging from the discussion using another color and on different sections of the page. The page then served as a collective memory or summary document, allowing participants to take ownership of the process. Participants in both cases opted to either keep the original (Case 1) or a copy (Case 2) of the drawing for themselves.

Some participants used their timeline as a record of events, often including the name of the hospital, health professionals, and dates deemed important and eliciting powerful and harrowing narratives. Stopping participants from writing these meaningful facts may prevent the disclosure of important narratives, while their inclusion could limit the ability to publish or save the document in its entirety as personal information may necessitate the

blocking out of some information to maintain confidentiality (see Figure 3). In both cases, participants understood and consented to the publication of their drawings in a peer-reviewed journal and were aware that although their names could be changed and any personal details removed, someone who knew them well may recognize them by their drawing or handwriting.

Providing individuals with an opportunity to verbally elaborate details about their timelines is crucial. In both cases, young people and parents chose different colored pens to add meaning and context to their experience, without which valuable meaning and understanding would be lost. The quote below highlights why this parent chose a red pen to portray their emotion and the importance of that specific event:

... it was a definite state of confusion. I'll write that down; I want a red pen for that one ... I got the hump and drove [my child] to [another hospital]. (Case 1, Parent)

In both cases, some participants drew symbols and/or illustrations, as described in other studies (Bagnoli, 2009; Gramling & Carr, 2004). Drawings can be open to interpretation and hard to analyze (Literat, 2013). In Case 1, nine young people (43%) chose to draw pictures on their timeline highlighting the preference of some young people to use visual communication. Participants who chose to draw pictures varied in age (from 11 to 18) and gender, suggesting that not only younger age groups or a specific sex were more likely to draw. Of the 38 pictures drawn, 18 (47%) were drawings of faces showing emotions, 10 (26%) were drawings of physical activities, and 8 (21%) illustrated friendships or social conflicts. None of the parents chose to draw pictures. Offering young people a mechanism for visual communication when they feel unable to communicate something verbally has been identified by other authors as important (e.g., Stewart-Tufescu et al., 2019).

Figure 2 is an example of why drawings should be combined with language-based methods to avoid misinterpretation. The young person drew a picture of fireworks at the end of treatment; without explanation, this could be misinterpreted as a celebration. However, the young person explains the fireworks represent how happy they would be: “I’d be feeling really, really happy, out of this world, like fireworks.” Equally, the facial expression at the start of Figure 2 was explained as being “scared” when they received a diagnosis because they “didn’t know what [the diagnoses] were.” In comparison, the facial expression at the start of Figure 4 looked like a smile, but they explained it represented “... the nausea ... I just always thought I was going to be sick” and then labelled the facial expression “nausea.”

In contrast, in Case 2, only two participants (one young person and one parent) chose to draw pictures on or within their timeline. Figure 5 illustrates an elaborately illustrated timeline, for which, without a more in-depth explanation, much of the young person’s treatment experience would have been lost. This young person explained: the intertwined floss (at the top of the page) reflected being “light

and carefree” prior to onset of chronic pain; bones represented “when everything was lost and exposed,” and puzzle pieces showed when the intensive treatment program provided the missing pieces to manage their pain.

Both cases found that timeline drawing and subsequent interviews were well received. Similarly, Looman et al. (2022) found young people rated the completion of a timeline as “easy,” described doing the activity as “fun,” and fewer than 2% of the participants opted out of one or more elements of the timeline method. Between both studies, all but one parent (in Case 1) chose not to complete the timeline; no reason was sought or given for declining to participate. This exception highlights that the timeline method may not be acceptable for some participants. Conolly (2008) found three out of the thirty-one socially excluded young women (aged between 12 and 16 years) expressed that they could not draw a timeline. Previous authors have suggested careful consideration be given to participants’ ability to physically write in the required language (Conolly, 2008; Kolar et al. (2015). Guillemain (2004) highlighted that for participants coming to terms with their condition and still making sense of it,

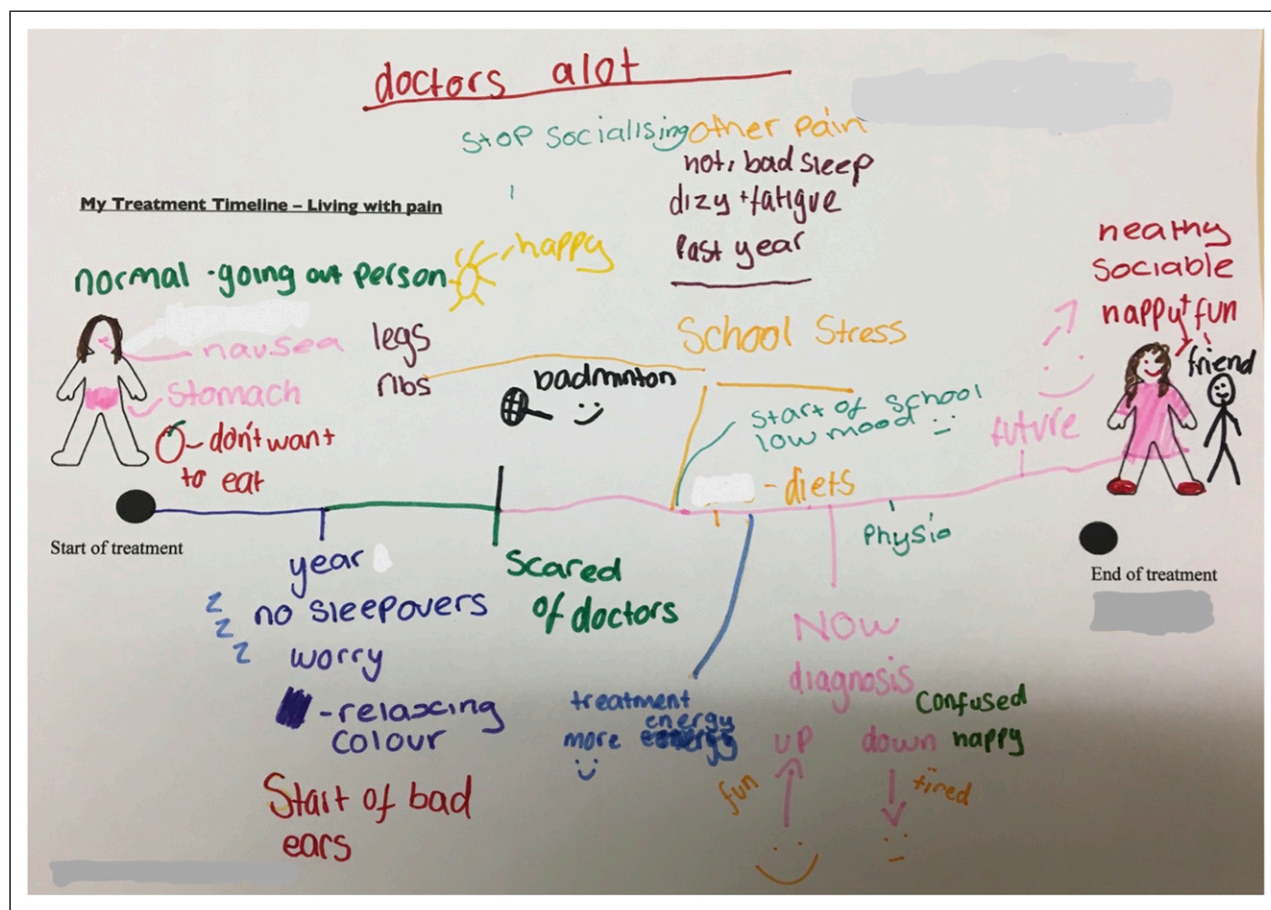


Figure 4. Example timeline drawn by a young person in Case 1.

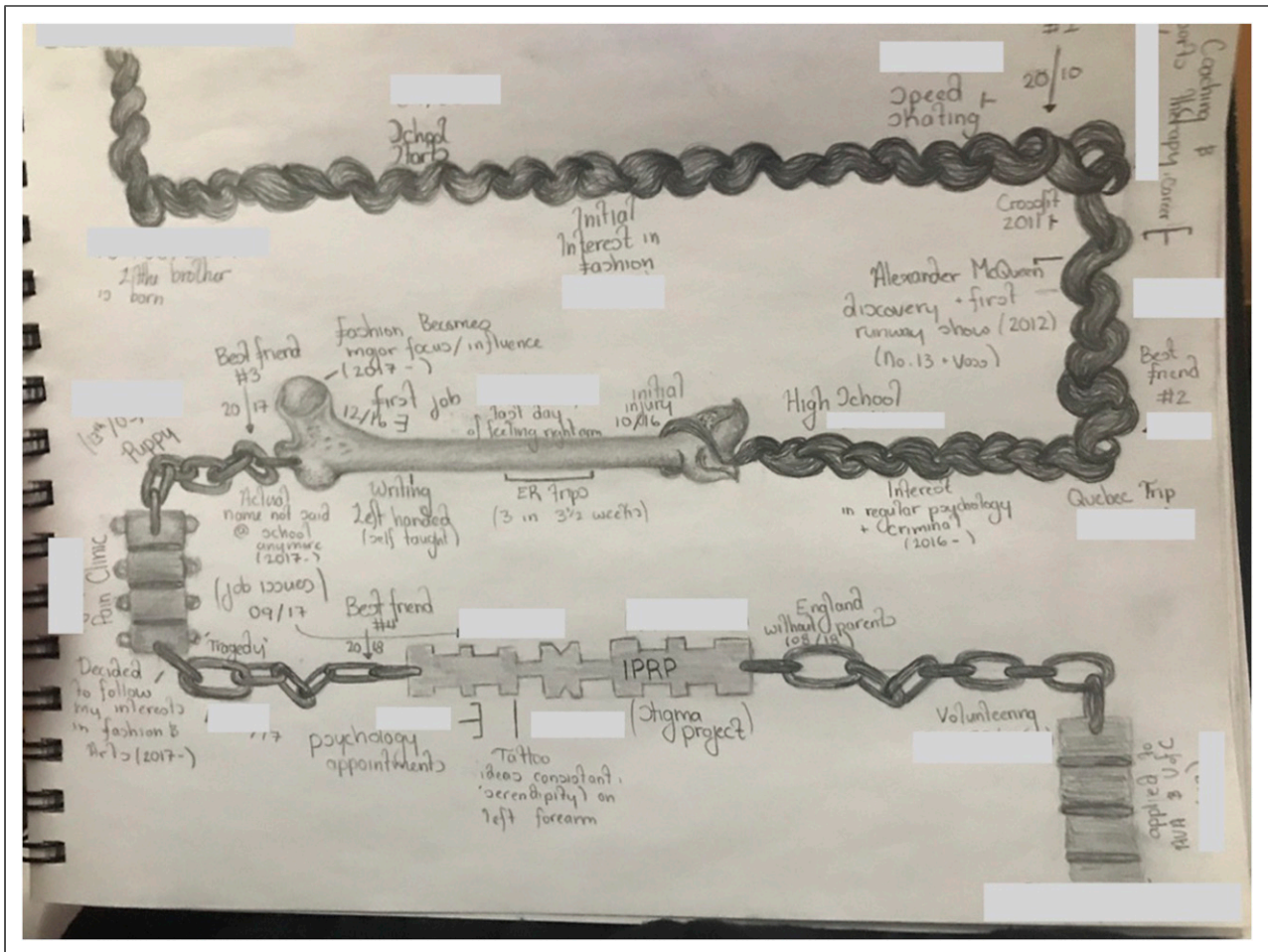


Figure 5. Example timeline drawn by a young person in Case 2.

being confronted with the reflection necessary to create a timeline may be too difficult at a particular moment in time. Reflecting on ways to adapt the method or transition quickly to another approach (e.g., interview only or the interviewer creating the timeline for the interviewee) prior to initiating data collection is recommended.

Across both cases, young people and parent engagement with the timeline creation demonstrated great variation. In Case 1, some participants prioritized writing on the timeline and almost covered every space on the paper which led to larger silences in the interview. Other participants preferred to describe their experience verbally pausing very briefly to write keywords at specific points. In Case 2, some participants began the interview with as few as 7 points on their timeline (see Figure 3), while others required multiple pages. Moreover, the timeline creation was reported to validate participants' pain experience, which can be empowering in and of itself.

Creating a Timeline Empowers Participants. Timelining is an approach reported by many study participants to be empowering, enabling them to frame their own realities, and providing them with a platform to articulate and reappraise their experiences (Kolar et al., 2015; Leung, 2010; Literat, 2013; Sheridan et al., 2011). The reflective nature of drawing and its narration through the interview process facilitate participants' exploration, conceptualization, and articulation of personal experiences and perceptions (Leung, 2010). However, the interview can become very personal and intimate and, as a result, must be managed with caution and emotional sensitivity. The interviewer should have the capacity to hold space for the intensity of the narratives as they unfold while keeping the salient themes of the research study at the forefront (Leung, 2010). Although timelines have been employed as a therapeutic tool, when using them in data collection, the interviewer should not counsel or intervene (Berends, 2011; Gramling & Carr, 2004).

While both being clinicians, we introduced ourselves to participants as researchers in the context of our studies. Being clinicians who regularly complete patient histories using a temporal framework may have contributed to the comfort level with the use of the timeline method. The approach also necessitated that our interactions with participants go beyond their chronic pain diagnosis, and instead viewed them as individuals, exploring their experiences and perspectives with humanity and caring, and without our typical problem-solving focus. Being aware beforehand of the deep human connection that is created in the use of this method allows the interviewer to be prepared and to guide the interview in an ethical manner (Adriansen, 2012).

Supported by existing timeline studies, both cases found young people and parents responded positively to the visual and participatory nature of timelines (Monico et al., 2020) and felt a sense of ownership over the process (Adriansen, 2012). The dialogue and responsiveness of participants during the interview have previously been noted to increase when referring to or writing on their timelines (Martsin, 2018). Moreover, this has led to participants uncovering details and information that otherwise may have remained unstated or inaccessible to researchers (Martsin, 2018).

In both cases, young people disclosed sensitive topics in writing rather than verbally on their timelines (e.g., the death of a family member and friend, suicidal ideation, self-harm, discovering gender identity, and police involvement). In Case 1, one young person who felt unable to verbalize an upsetting experience with a health professional instead wrote on their timeline “told I was overweight and that was the problem.” While most young people discussed these topics in more detail, often the actual words on the timeline were not spoken out loud but instead were referred to by indicating the words on the paper. Sensitive topics such as drops in their mood were frequently written at the bottom of a downward curve and could be written in the response to the probe “What happened here?” when pointing to that point on their timeline. This is demonstrated in Figure 2 when “sad” is written at the bottom of the curve.

In Case 2, young people and parent participants reported that creating the timeline assisted in remembering and organizing their thoughts, created a place to begin the conversation, and helped to put them at ease.

I think it is worth writing it down. It gives us a “talking” place. The other thing it gives us is that we don’t have to do as much eye contact. Being an introvert, I think it’s better. (Case 2, Parent)

Adriansen (2012) supported this parents’ reflection and highlighted how the reduced need for eye contact when

drawing contributes to creating a “safe space” (p. 47) and that the atmosphere of presence was like talking while driving or walking.

Seeing a visual representation of one’s life journey can be illuminating for some, but also upsetting and disturbing to others (Sheridan et al., 2011). In Case 1, one of the young people expressed the benefit of drawing their journey and how they had verbalized things they had previously not talked about.

This is a really good idea, this helped a lot, like drawing it out on this ... it’s been useful talking about what I felt throughout the whole thing and there’s actually a lot more than I thought, that I felt about in a way like I’ve never really talked about. (Case 1, Young Person)

At the end of the interview, a parent also reflected on their finished drawing and expressed the importance of being given the opportunity to talk through their whole journey.

It’s been nice to be able to kind of see the journey [on the timeline] and you know, let it out. Sometimes you spend so much time keeping in control, you know, yeh, putting on a brave face, sometimes you just can’t. (Case 1, Parent)

In Case 2, some participants reported that creating the timeline gave them perspective on their improvements as they related to their pain, as well as their journey in relation to other life events. For others, illustrating the timeline saddened them, bringing them to a realization of a perceived lack of improvement or even regression that had occurred since the treatment. Others used it as a wake-up call, identifying a relapse in their ability to self-manage, a need to review the concepts learned in treatment, and a motivation to reintegrate strategies previously recognized as being helpful. Some used it as an opportunity to have difficult conversations about what was realistic for their future, as expressed by this young person:

I guess it was a little saddening for me just because, when I was doing the before timeline, I was getting excited because I was just thinking about how things could be. But, when I was doing the after-timeline, I was talking to my dad about it [and questioning] “Is this realistic, do you think?” and I could tell that it was kind of making him sad too. (Case 2, Young Person)

Timelines Are Temporal, Capturing Change Over Time. Time is an important feature of the participants’ stories (Leung, 2010; Sheridan et al., 2011). As shown in the presented cases, timelines provided structure and context to the interviews. Participants reflected on their/the young

person's condition, their journey with it, and their associated experiences, using the temporal dimensions of the past, present, and future (Sheridan et al., 2011). Life events can be placed within a context (Bagnoli, 2009; Gramling & Carr, 2004). In this parent quote, a mother looks at the events on the timeline and reflects on a specific point she changed which led to a positive change in the young person.

... There's an intangible thing there [pointing on timeline] where I changed, as [their] parent I changed and if I look back at some of the events now ... I was sort of paralyzed by fear a bit, where now I'm just ballsy and I don't care and I'm like, I want [them] better. (Case 1, Parent)

When events and experiences were displayed along a timeline, this parent considers the wider contextual influence of having the house renovated in relation to the young person's pain starting and improving.

... it has been a bit of a tough 2 years 6 months because we did this big house extension as well so that completely threw things into chaos a little bit as well. And certainly, saying that, that seems to also have been better in the last sort of months or so, behavior and everything seems to have improved and actually seems to have improved and whether that is directly linked or whether that is just you know the time of his life and puberty and all the rest of it, I don't know. (Case 1, Parent)

These quotes support how timelines allow for connections between and across events (Monico et al., 2020), a feature that could address the aims of the two cases and allow the complex interplay between social, psychological, physical, academic, and environmental factors to be conveyed.

Timelines offered a way for participants to display their treatment course and trajectory, making the culmination of experiences and adversities explicit (Monico et al., 2020). A treatment course is often defined by health professionals as the time between the first assessment and the point of discharge from a specific service. What was apparent and important in these two cases was that participants viewed their treatment course differently. In Case 1, the participants marked where they perceived themselves to be along the treatment course with an arrow or phrase such as "I am here." Although healthcare professionals perceived some young people to be at the start of their treatment, young people and parents made links with previous pain or health experiences, not recognized or established by the health professional, and considered themselves to be mid-way through treatment. In Case 2, some participants took their timeline back to their birth or early childhood, linking their early memories and experiences to their current chronic pain experience.

Researchers using timelines to explore a treatment experience need to be prepared that a treatment course from the perspective of the young person and parent did not have pre-defined boundaries. Recruitment of participants at specific points of the treatment course using numerical values (months of treatment) may hold relevance for health professionals, but participants may link months and years of previous treatment to their current episode of care.

Both cases explored the future with their participants. Case 1 found that young people over 11 years were able to place events in the past and into the future. However, as found by Crivello et al. (2009), the future was less detailed than the past. The future endpoint explored in Case 1 was when hospital treatment was no longer required. This allowed an ideal recovery to be discussed. While all participants could describe an ideal recovery for themselves or their child, two young people left a gap in their timeline between where they were and their ideal endpoint. The gap allowed the young person to communicate visually that they currently did not foresee achieving their ideal endpoint, which has important clinical implications.

Similarly, in Case 2, when participants were asked to construct a timeline of their future, both parents and young people produced timelines with much less detail, with some adopting a completely different shape (e.g., circular) than their past and present timelines. Most identified typical adulthood milestones such as moving out of the family house, post-secondary trajectory to a career, a job, relationships, and family aspirations. Recalling experiences in the past can be affected by recall bias (Van Den Brink et al., 2001). It is important to note that when exploring young people's healthcare experiences, memories and the way events have been constructed into a narrative are of primary importance. Noel et al. (2012) found that a young person's memory of a pain experience influenced future experiences and supported the need to understand how an experience has been remembered from the young person's perspective. The timeline approach uses the bias of recall to understand the importance placed on these memories.

Discussion

The aim of this article was to illustrate the application and the flexibility of the timeline method and provide scaffolding for other researchers interested in considering its use to gather information about young people's and their parents' experiences with healthcare treatment. Our research experience highlighted several implications which we believe are worthy of sharing and are presented here as our reflections.

Authors' Reflections

First, there was no right or wrong way of engaging participants in the timeline process. The timelines created and the interview responses elicited are as unique as the individual participants themselves.

Second, the complexity of the timeline is not representative of the subsequent interview process. Fewer words or pictures on the timeline did not equate to less engagement with the interview or richness in the interview data generated. In-depth and rich data were gained by giving participants the freedom to communicate in a way that had meaning and was familiar to them.

Third, flexibility is an important component of this method. Providing the opportunity to complete the timeline before or during the interview appeared to create a safe space and empowered participants to lead the interview agenda. Freedom to use drawings, different colors, various line orientations, and written or spoken words meant participants could convey sensitive information using a method of their own choice, eased anxiety, increased comfort, and allowed the development of a trusting relationship.

Fourth, the activity (i.e., creating the timeline) appeared to validate the pain and healthcare experiences. Past treatment could be explored, but so could a future treatment endpoint and participants' beliefs of what could and could not be achieved. While for most the method was empowering, some participants reported negative thoughts and feelings (e.g., hopelessness, sadness, loss, and depression) about their progress and/or their future. Planning for a positive closure and additional support when concluding the interview process should be considered.

Lastly, the visual representation of events and experiences was important, as were missing aspects of life which also held connections and could be further reflected upon and explored. This delicate and complicated network of connections across personal, family, and contextual factors evolved over time and for some was visualized on a timeline for the first time. The timeline method highlights triggers, associated events, and contributing factors to the pain and treatment experiences, which had previously not been considered or explored. As a result, giving participants the permission and freedom to communicate in a way that had meaning and was familiar to them provided in-depth and rich data and gave rise to research themes that would otherwise not have been discovered. It also allowed some participants to unveil new aspects of their condition previously left unaccounted for.

Based on these reflections, we provide the following five guidance points to other researchers wishing to apply the timeline method to an interview process exploring the experience of young people with chronic conditions

and/or their caregivers, as it relates to their healthcare treatment and interactions with services.

Guidance Points

1. Involve young people affected by the health condition being explored, and their parents/caregivers (as appropriate), at the study design stage when considering the use of the timeline method. Their knowledge and insights are crucial to implementing the timeline method successfully.
2. Provide participants with an array of tools (e.g., paper and colored pens), permission, and encouragement to feel free to communicate in a way best suited and is most meaningful to them. This freedom is key.
3. While the concept of "line" (or sequence) is critical to the timeline method, the orientation (e.g., horizontal, vertical, and diagonal) and form (e.g., straight, wavy, and list-like) should be chosen by the participants based on their preferences, to represent their unique experience and healthcare journey.
4. Carefully explore drawings or illustrations, color choices, labels, line orientation, or symbol placement during the interview process to ensure correct interpretation.
5. Consider incorporating a positive closure to the interview process by exploring the future, a person's resiliency, and/or how healthcare services and experiences can be improved for others.

It is our hope that by sharing these reflections and providing guidance, we can inspire other researchers to consider using this method in their healthcare service research.

Limitations, Clinical Implications, and Future Research

The guidance provided should not be applied without considering the following limitations. First, both cases described in this article involved young people who were closer to adolescent age (>11 years) or young adults, and therefore, due to language, social, and contextual differences, the method is likely to need tailoring for use with younger children. Second, while the studies were completed in different countries, English and Canadian health structures and demographics have similarities, and therefore the acceptability of the method and the experiences of healthcare may differ in other countries. Finally, although this article focuses on using this method to explore treatment experience in young people treated for

chronic pain, we believe this method could be used with other patient populations, but additional research is required to validate this hypothesis.

In addition to its further application in future health research, we also foresee clinical implications for the timeline method as part of a comprehensive chronic pain intervention for young people and their parents. Our findings suggest that if used alongside a patient or family interview, timelines could facilitate young people and their parents in re-telling their narratives, helping validate their experiences, and offering an alternative approach to exploring person-centered goals to focus treatment. Timelines may also be useful as part of counselling interventions (e.g., psychology and family therapy) and/or behavior changes, assisting young people and their families to identify and raise awareness of triggers, precipitating events, and unhelpful behaviors which may otherwise have remained hidden. These examples demonstrate not only the clinical relevance of the timeline method but also how timelines could be used to highlight the multiple interacting mechanisms and components of a comprehensive chronic pain intervention and facilitate change in various behaviors in those delivering the intervention as well as those receiving it. Chronic pain interventions are complex. Future research aimed at exploring the use of the timeline in a clinical intervention will need to adopt a complex intervention framework (Skivington et al., 2021) in determining its utility.

Conclusion

This article aimed to provide sufficient evidence and details to encourage and guide others to consider the timeline method in exploring the healthcare experiences of young people with chronic conditions and that of caregivers. The use of the timeline method offers a creative flexible person-centered approach. The interaction between the visual display of the timeline and participants' explanations can validate experiences and empower participants, while the researcher gains insight into the underrepresented healthcare users' experience from a temporal perspective. Such insights are key to improving the quality of care received and making fundamental changes to what and how healthcare services are delivered and how healthcare research will be conducted in the future.

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Informed Consent

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