

Commentary

“Nothing about us without us”: The route to developing useful participatory activities for adolescents with chronic pain

Line Caes and Jessica Fales

Background

Many adolescents with chronic pain experience disruptions to their social worlds, including difficulties in their peer relationships (Forgeron et al., 2010). The reasons for these peer problems are not well understood, though some have speculated that social competency deficits in the presence of pain may contribute (Fales & Forgeron, 2014). Understanding how adolescents with chronic pain navigate their social worlds - and how they react and respond to the unique social challenges that they experience - can offer critical insight into why some youth with chronic pain may be at greater risk for peer relationship problems.

Social competence is a multidimensional construct, the core components of which involve the ability to effectively select and enact appropriate behavioral strategies in challenging situations (Nangle et al., 2010; Flannery & Smith, 2017). At present, systematic research investigating the social competencies of adolescents with chronic pain has been hindered due to measurement issues. While measures of social competence exist, they were developed and validated in healthy samples and may not be reliable or valid for adolescents with chronic pain. The purpose of this commentary is to illustrate the design of an interactive participatory workshop, as a first step in co-developing a new instrument to assess social competence with and for adolescents with chronic pain.

We used the broad principles of measurement development offered by the Standards for Educational and Psychological Testing (American

Educational Research Association, 2014), in conjunction with Goldfried and D’Zurilla’s (1969) behavioral analytic model for assessing social competence, as the framework for our co-development process. Inherent to both models is the reliance on experts to determine measure content, including items and response options. The first step of the Goldfried and D’Zurilla model requires a comprehensive assessment of all of the difficult or challenging social situations that adolescents with chronic pain encounter. In accordance with the growing literature on the benefit of patient involvement and engagement in research, we felt that the adolescents themselves would be the best source of information and could serve as experience experts. Indeed, patient involvement, especially using qualitative methodologies, has been shown to encourage empowerment and freedom to express issues relevant to their situation, thereby generating rich, detailed and valid data (Bender & Ewbank, 1994; Carter, 2004; Kellett, 2010). The participatory research process (PRP; Kellett, 2010) in particular is a well-established and suitable process to enhance our understanding of the health and well-being of adolescents by creating an environment where researchers and adolescents interact as equals and adolescents can share their unique, expert point of view (Gibbs et al., 2018).

Thus, for our purposes an interactive participatory workshop using PRP guidelines was designed to elicit the social situations that adolescents with chronic pain find most challenging. The first difficulty we faced was a lack of standard

guidelines regarding how to develop or structure these activities. Furthermore, scientific articles describing the use of such PRP techniques do not go into detail on their development process. Hence, the goal of this commentary is to describe the development, and encountered challenges, of an interactive participatory workshop to inform the development of a tool to assess social competence in adolescents with chronic pain.

Development of the interactive participatory workshop

We initially consulted with a PRP expert, Dr. O'Higgins (O'Higgins & Nic Gabhainn, 2010), for guidance on strategies to ensure adolescents within the workshop felt empowered to contribute their experiences and to minimize the standard power relationships in data collection by placing the adolescents, rather than the researchers, in the expert role. Dr. O'Higgins highlighted the importance of (1) group size (limiting participation to 20 in total who can be split into smaller collaborative groups of 3-5); (2) pacing, including putting time pressures on the planned activities; (3) keeping activities fun and colorful; and (4) ending on a positive note. In brief, the interactive participatory workshop we developed followed a carefully timed *think, pair, share* structure, wherein participants first came up with as many challenging social situations as possible on their own (situation elicitation), then transitioned to small groups for a SNAP game (O'Higgins & Nic Gabhainn, 2010). During the SNAP game, named to reflect the quick pace of the activity (like snapping your fingers), small groups are formed during which participants shuffle and then sort their elicited social situations into categories that contain similar social situations. The SNAP game ends with labeling or naming each category. In the next phase, the results of the SNAP game are shared with the full group, followed by the final phase in which positive solutions to the most frequently identified challenging social situations are generated (see Appendix for details and instructions; authors can be contacted for further information).

Once developed, the workshop was first tested with three developmental psychology colleagues. This step was not only crucial for the researchers to

practice and gain confidence with the execution of the procedures, but also to gain input from experts on developmental psychology regarding any anticipated difficulties. Indeed, while the procedures worked well and were deemed feasible, several potential problems were identified. For instance, everyone had received a different color of paper to write their situations (e.g. Olivia received green colored paper, while Emily received blue colored paper; pseudonyms have been used) and it was expressed that this could identify whom wrote down the situation during the SNAP game. Furthermore, it was deemed that the color red might be problematic as that is often associated with negativity or dangerousness (Moller et al., 2009). Hence, we were advised to avoid the use of red and ensure that each participant would have access to a variety of colored paper on which to write their situations. In addition, in this testing session we had not clearly or carefully explained the various activities that would take place. Consequently, some were surprised to learn that their individually elicited social situations would be shared with the group. Additionally, there was confusion regarding the sorting procedure during the SNAP game. In response, we changed the verbal instructions to make all four phases very explicit (see Appendix).

In a final step before soliciting collaboration from adolescents with chronic pain, we had the opportunity to test out the procedures and seek feedback from a group of pain-free adolescents ($n = 15$) and their parents. Beyond providing the researchers with further confidence in executing the workshop (the activities were very well received by both adolescents and parents), two new, unanticipated take home messages were learned. First, the researchers found the parental participation informative and reinforcing of the idea to include adolescents within the participatory research process, as adults identified very different challenging social situations compared to the responses generated by their children. Table 1 includes the different social situations identified by adolescents versus parents. Only two situations were identified as challenging by both adolescents and parents: public speaking and meeting new people. Furthermore, the adolescents described difficult social situations that neither the researchers

Table 1
Difference between difficult social situations elicited by pain-free adolescents compared to their parents

Adolescent-elicited social situations	<ul style="list-style-type: none"> ▪ being stuck in the middle of two friends in an argument ▪ falling out with a friend and then having to interact with them ▪ when your friend leaves you with a group of their friends ▪ mistaking someone for a friend ▪ teaching the rest of your class – displaying knowledge ▪ being the first person in the class at school ▪ walking into the wrong class ▪ working and getting to know strangers
Parent-elicited social situations	<ul style="list-style-type: none"> ▪ disagreeing with the majority opinion of a group ▪ bereavement (e.g. parent death) ▪ keeping a secret ▪ family gatherings ▪ small talk ▪ wanting to stay longer at an event/party and your peer doesn't want to ▪ break ups ▪ conflict over social media

nor the parents would have identified to be challenging (e.g. being the first person in the class at school). This further confirms the critical importance of listening to the adolescents themselves, who are the experience experts, rather than relying on proxy report by parents. Secondly, reflecting on the category names chosen by adolescents during the SNAP game (see Table 2 for examples) revealed the importance of having adolescents create the category labels, which reflect

their own, rather than the researchers' language and interpretation. This further reiterates that co-production of a measurement tool is key to understand and use the language of adolescents rather than force our language onto them. Follow-up workshops using our procedure in Scottish adolescents with chronic pain have proven to work well to elicit a variety of difficult social situations, thereby further reiterating the feasibility and importance of adopting a co-production process.

Table 2
Labels chosen by pain-free adolescents during the SNAP game

Socializing with new people	Impression you have on people	Peer pressure
Meeting new people and having interactions	Feeling like you're being judged	A situation where you feel pressured into doing something to fit in
Not wanting to go somewhere and your friends make you and then they leave you with people you don't know	Feeling judged: walking into a room and feeling judged by your appearance/impression you have on people	Peer pressure of things you don't want to do

Next steps

The several steps taken to systematically and thoroughly test the interactive participatory workshop were extremely valuable as they raised a number of questions and highlighted potential challenges that facilitated further refinement of our PRP techniques. We now have a systematic plan for executing and addressing potential challenges within future workshops. Now that we are confident that our interactive participatory workshop works well, engages adolescents, and elicits meaningful descriptions of challenging social situations, we are enthusiastic to take this work to the next step:

Line Caes, PhD

Division of Psychology, Faculty of Natural Sciences, University of Stirling, Scotland, UK
email: line.caes@stir.ac.uk

Jessica Fales, PhD

Department of Psychology, College of Arts and Sciences, Washington State University, WA, USA

conducting interactive participatory workshop with adolescents with chronic pain across the United Kingdom, USA and Canada. Active involvement of adolescents with lived experience with chronic pain is crucial in developing appropriate assessment tools to ensure the tools are capturing their experience comprehensively and are able to pick up on subtle differences and challenges. Such co-designed assessment tools will facilitate the early identification of difficulties in social competence and the provision of tailored support to adolescents with chronic pain who experience challenges in navigating their social world.

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Appendix: Interactive participatory workshop schedule

All phases were carefully timed to ensure the adolescents had enough time to complete each activity, but not too much time in order to avoid boredom.

Phase 1: Individual situation elicitation (10 min)

Participants individually brainstorm their perceptions of challenging, difficult or awkward social situations. They are instructed to generate at least 15 ideas, writing each idea down on a separate sheet of colored paper. They are advised that the task is timed, and that they are to come up with ideas as quickly as possible. They are also advised that they can identify situations that didn't happen to them.

Specific instructions given to participants:

"As quickly as possible, we want you to list at least 15 social situations or activities with peers (people who are the same age as you) that are difficult or awkward. These can be situations that have actually happened to you—or they can be situations that you've just heard about happening to friends or worry about happening. Write each situation or activity on a different piece of colored paper. After this you'll play the SNAP game where you will be sharing the situations with each other in small groups of maximum four people."

Phase 2: SNAP game (15 min)

In groups of four, the youngest person gathers all the colored pieces of paper within their small group and starts the SNAP game. The SNAP game, developed by O'Higgins & Nic Gabhainn (2010), aims to identify commonality amongst the elicited challenging social situations in a fun and snappy way, due to the time limit of completing this in 15 minutes:

- Mix up the colored pieces of paper
- Deal out each individual colored paper face up
- Sort into piles of similar situations
- Give a name to each pile that describes the category

Specific instructions given to participants:

"We will now play the SNAP game. In your small groups of four, you need to find out who the youngest of the group is. (pause while they do this).

This person will gather all the pieces of colored paper and mix them up. After mixing up the pieces of paper, the youngest person deals them out face up on the table, so that all the pieces of paper are visible to everyone at the table. Then within your group you need to sort the situations, by putting the situations that are similar together in one pile. Once you are finished putting the situations together in piles based on how similar the situations are, you need to give a name to each pile. This all needs to happen in 15 minutes, so no time to lose!"

Phase 3: Sharing (5-10 min)

After every group has finished labelling/naming their various piles of situations the groups are asked if they willing to share the categories that they have come up with to see if the different groups came up with similar or different categories. Not every group needs to share, this is voluntary and will depend on how much the groups want to share.

Specific instructions given to participants:

“Does anyone want to share the names of their piles of situations they have formed?”

Phase 4: Solution generation (10-15 min)

The final phase aims to stimulate adolescents to share positive ways to overcome some of the reported challenging social situations. In the small groups, participants chose one particular category that they want to continue working with. This can be the category that was most frequently mentioned, or the category that they find the hardest or the category they like the most.

On a large piece of white paper, the label of the chosen category is written in the middle. Within the small groups, participants are asked to come up with as many ways to overcome this difficult situation, without introducing any new problems.

Specific instructions given to participants:

“Select one pile of situations that you want to continue working with. This can be the pile of situations that is difficult or awkward for everyone in your group, or the pile with the most difficult or most awkward situations or Once you have selected the pile of situations to continue working with, write the name of that pile in the middle of the big piece of white paper in front of you. Try and come up with as many solutions for these difficult or awkward social situations as you can and write them on the big piece of white paper.”