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Adolescents' experiences of Help Overcoming Pain Early—A school based person-centred intervention for adolescents with chronic pain

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Abstract

To illuminate adolescents' experiences of Help Overcoming Pain Early (HOPE), a person-centred intervention delivered in a school setting by school nurses. Twenty-one adolescents with chronic pain recruited from secondary school, who had completed the HOPE intervention, were included in the interview study. The HOPE intervention was built on person-centred ethics and consisted of four meetings between school nurses and adolescents on the subject of stress and pain management. A qualitative method using content analysis with an inductive approach was employed. In the interviews, the adolescents describe how they reclaim their lives with the help of HOPE. They use different strategies and parts of the intervention to move on with their lives. A trustful relationship, as that with the school nurse, was essential to dare to change. The overarching theme summarizes in *Becoming myself again* and is built up by three sub-themes: *Trust a pillar for growth*, *Making sense of my life with pain*, and *Putting myself into the world again*. A person-centred intervention such as HOPE applied in a school context is promising for promoting confidence in adolescents with chronic pain. A trust-building process emerged, in terms of both the adolescents' trust in the healthcare staff they meet and their confidence in their own ability to handle and influence their situation, which in the long term can promote trust in themselves as a person.

KEYWORDS
adolescent, chronic pain, interview, school health

1 | INTRODUCTION

Chronic pain, defined as recurrent or consistent pain for at least 3 months, has become a significant public health problem globally and a leading cause of morbidity in children, negatively impacting their emotional, physical, and social development and functioning.[1,2] The prevalence is increasing among adolescents and an international study comprising 42 countries found that 44% of adolescents had experienced problems with pain each week during the previous 6-month period.[3] The problem is estimated to be even larger in low- and middle-income countries.[4] Chronic pain could present as a symptom or a syndrome with widespread pain. The most commonly reported pain localisations in adolescents with chronic pain are the head, abdomen, back, neck, and extremities.[3]

Chronic pain has implications for adolescents' health in terms of poor physical disability, mental ill-health (e.g., anxiety, depression, sleep problems), and poor academic performance.[5,6] Adolescence is a critical period that determines health trajectories across the life course[7] and the presence of chronic pain predisposes them to other chronic health problems later in life.[8] Negative psychosocial health factors such as psychological problems (e.g., depression and anxiety), are related to a higher incidence of chronic pain in adolescents.[6]

For the above reasons, early interventions are necessary to prevent the progression of pain.[9] As school is the adolescents' working environment, it is advantageous to deliver interventions in a school context. In Nordic countries, school nurses often provide first-line care for adolescents with chronic pain.[10] However, according to the school nurses themselves, the available interventions are not sufficient to treat chronic pain in adolescents.[11,12] Management of chronic pain requires a broad approach and strategies other than pharmacological treatment.[13] Students have requested initiatives with approaches adapted to their individual health situations and needs.[14] Moreover, a person-centred care (PCC) approach has been called for to facilitate healthcare professionals' management of chronic pain in adolescents.[15]

As a response to the gaps identified above, we designed the Help Overcoming Pain Early (HOPE) intervention, a 5-week pain management program with a PCC approach, as an add-on to standard school healthcare.[16] HOPE was based on the PCC framework developed by the University of Gothenburg Centre for Person-Centred Care (GPCC) containing ethical principles in which the perspectives of patients and healthcare professionals are equally important.[17] HOPE was evaluated in an RCT design in Sweden and was found to have a significant effect on self-efficacy in the sub-group of adolescents at secondary school.[18] To further explore the students' views on the intervention and thereby gain more in-depth knowledge about PCC for future interventions, the present study investigates how the participating adolescents experienced the intervention.

2 | AIM

The aim of this study was to illuminate adolescents' experiences of HOPE, a person-centred intervention delivered in a school setting by school nurses.

3 | MATERIALS AND METHODS

3.1 | Help Overcoming Pain Early

As mentioned above, HOPE was based on the ethical PCC framework developed by the GPCC and built on a participatory design, in which adolescents with chronic pain and school nurses contributed to its development.[11,19] School nurses who were to provide the HOPE intervention underwent a 1-day training program containing the component of PCC, neurophysiology, concrete suggestions for stress and pain management as well as a gender perspective. The training program for the nurses was provided through lectures, written materials, and videos. Thereafter, adolescents who fulfilled the inclusion criteria met a school nurse at their school on four occasions.[18] These four occasions were built on the three routines set up by GPCC to ensure PCC, that is, (a) initiating a partnership by eliciting the adolescent's narrative including his/her goals, capabilities, and limitations; (b) creating a partnership through co-creation of a health plan that promotes the adolescent's self-efficacy and self-management; (c) documenting the adolescent's story and health plan.[18]

3.2 | Study design

A qualitative study design was used to achieve the aim of the study, with semi-structured interviews as the basis for data collection. The study is described according to the Standards for Reporting Qualitative Research (SRQR) to ensure a transparent description of the applied methodology.[20] The original randomized controlled trial (RCT)[18] was registered as NCT02944786 in Trials.gov Identifier.

3.3 | Qualitative approach and research paradigm

In this study, we chose content analysis, as it enables the interpretation of meaning from interviews performed in a clinical setting and adheres to the naturalistic paradigm. We decided to use the conventional inductive approach, in which categories are derived directly from the text data.[21] The advantage of using the conventional approach is that direct information is gained from the participants without imposing preconceived categories or theoretical perspectives.

3.4 | Participants and selection process

In the present study, 21 adolescents with chronic pain (mean age 14.84 years, range 14–15 years) who took part in HOPE and attended secondary school were asked to participate. These 21 participants constituted a subgroup of the 98 adolescents who participated in the HOPE intervention. They were recruited from public as well as private secondary and upper secondary schools with various socioeconomic contexts in cities, small towns, and rural areas in the south-western and south-central regions of Sweden. A total of 20 out of 21 participants completed the interviews, as one was unable to participate due to falling ill and thereafter changed schools, thus having a different school nurse. Of the 20 participants interviewed, 18 were girls and 2 were boys.

3.5 | In-depth interview process

In-depth interviews were conducted with the 20 adolescents taking part in a 3-month post-intervention between December 2016 and

November 2019. They were interviewed by the first author (UW), using a dictaphone to record the interviews. The interviews (mean duration 23.57 min, range 08.30–53.03) were transcribed by an authorized secretary.

All interviews began with an open-ended question, "How did you experience your situation and your problems before you met the school nurse?" The semi-structured interviews were based on an interview guide with follow-up questions to deepen the dialogue regarding how adolescents experienced their situation and their complaints after the intervention, as well as their perceptions of meeting the school nurse and participating in the intervention. Examples of follow-up questions were "Could you give an example of what you mean…" and "Could you describe more in detail what that was like for you?" Although the interview guide remained unchanged, the interview technique was refined over time. The interviews took place at the adolescents' schools ($n = 17$) or by telephone ($n = 3$) when a meeting in the school setting was not possible.

3.6 | Researchers characteristics and reflexivity

In order to facilitate a broad understanding of the studied phenomenon, the research team consisted of four healthcare professionals with several competencies and different experiences. The first author (UW) is a registered physiotherapist, a specialist in mental health, and a psychotherapist (basic education) with a focus on children and adolescents. The second author (SN) is a registered nurse with experience in pediatrics and research in the field of pain in children and initiated this RCT study. The third author (HW) is a registered pediatric nurse, with experience as a school nurse and in research in pediatrics, who contributed in-depth knowledge of qualitative research and methodology. The last author (ML) is a registered physiotherapist and professor, who contributed expertise in qualitative research methodology and chronic pain.

None of the researchers were involved in delivering the intervention or in the adolescents' usual care. However, the first author (UW) conducted all the interviews, and to prevent undue influence between her preunderstanding and the data we used an interview guide. Moreover, her interview technique and the way she adhered to the interview guide were scrutinized by the other researchers to ensure that the phenomenon under study was covered.

To ensure trustworthiness, we worked systematically with reflexivity throughout all phases of the research process, including the formulation of the research aim, data collection, data analysis, and drawing conclusions.[22–24] We adhered to the following definition in which reflexivity is described as "turning of the researcher lens back onto oneself to recognize and take responsibility for one's own situatedness within the research and the effect that it may have on the setting and people being studied, questions being asked, data being collected and its interpretation."[22] In more concrete terms we reflected on the location and influence of the researcher in relation to the environment. The adolescents were therefore invited to be interviewed at their own convenience (either in school or by phone). We also discussed the pros and cons of the professional status of the interviewer. The main author is a registered physiotherapist with extensive knowledge of and expertise pertaining to adolescents with pain, which might have influenced the way the interview was conducted. We concluded the added value of in-depth knowledge of bodily experiences and movement was essential for the quality of the interviews. Moreover, to capture the essence of the phenomenon under study, we considered it valuable that the interviewer had in-depth knowledge about pain and PCC.

3.7 | Ethical aspects

The study was conducted in accordance with internationally accepted ethical principles for medical research involving human beings, people through the such as the voluntary nature of participation and the freedom to withdraw at any time, as set out by the Declaration of Helsinki.[25] Adolescents, as well as guardians of adolescents younger than 15 years of age, provided written consent to participate in the study. It was agreed that should any of the participating adolescents exhibit serious symptoms of depression or suicidal thoughts during the interview either the adolescent or the interviewer would inform the school nurse, who would contact appropriate health personnel. All data were encoded according to the coding ID specified at inclusion in the study, and the files were subsequently stored in accordance with ethical codes and Swedish law. The study received ethical approval from the Regional Ethics Review Board in Gothenburg (Reg. No. 172-16).

3.8 | Data analysis

The transcribed interviews contained 139 pages in total and were analyzed in an iterative process, in accordance with content analysis as described by Graneheim and Lundman.[26] We used latent and manifest content analysis. Latent content analysis implies encoding and interpretation of the underlying meanings of the text, in this study presented in themes and sub-themes. Prior to the analysis process, a plan was made to promote credibility and trustworthiness.[27] By reading all the interviews to gain an impression of the material as a whole, meaning units relevant to the aim were extracted. Their content was condensed into codes and sorted into categories in order to describe and provide a representative illustration of the manifest content of the material. The content was then abstracted to produce the latent content, resulting in sub-themes. Based on these, a central theme emerged in accordance with Graneheim and Lundman.[26] By interpreting the latent content, qualitative content analysis can be used to reveal the depth as well as meanings of participants' expressed experiences.[28]

The first and the last author analyzed all interviews, and the last author contributed methodological support throughout this process.

The second and the third author entered the analytic process when the categories had been sorted, and all authors collaborated to define sub-themes and themes until consensus was achieved. This iterative process was refined over the course of several meetings. Such internal validation is considered valuable for the credibility of qualitative studies.

First, the credibility of the analysis was ensured by another analysis carried out by the second author, who read all the interviews to gain an impression of the material as a whole. He then examined sentence units, condensed sentence units, codes, and sub-themes to detect any bias in the initial review made by the first and the last author. Finally, the analyses were compared. To increase reliability, triangulation was used during the analysis, whereby the authors attempted to achieve consistency. In addition, representative quotations from the transcribed text were selected.[28,29]

4 | RESULTS

An overarching theme and three sub-themes emerged in the analysis of the interviews with the adolescents. The overarching theme was *Becoming myself again*, and the subthemes were, *Trust as a pillar for growth*, *Making sense of my life with pain*, and *Putting myself into the world again* (Figure 1).

4.1 | Overarching theme: Becoming myself again

The overarching theme describes how the adolescents who participated in *HOPE* experienced regaining their identity and becoming themselves again. The theme was divided into three sub-themes that together illustrate adolescents' thoughts and perceptions about how HOPE contributed to their development. In the overall theme, HOPE emerged as a process in which the adolescents could regain their self-confidence and gradually win back trust in their bodies by means of person-centred support from the school nurse. In the interviews, the adolescents described how they reclaimed their lives with the help of HOPE. They used different strategies and parts of the intervention to move on with their lives. A trusting relationship, as that with the school nurse, was essential for daring to change.

The theme and sub-themes are described in more detail below, with quotations from participants to illustrate and reflect their voices.

4.1.1 | Sub-theme: Trust as a pillar for growth

Trust was identified as a pillar that was fundamental for growth. It is clear from the adolescents' stories that trust was created by the school nurses' ability to listen and take their problems seriously, something the adolescents felt had previously been lacking. By taking the adolescents' previous experiences and knowledge into account and by emphasizing their wishes and interests, the school nurse was considered a person to trust.

> We have talked about a lot of things… not only stress but also the cause, that my childhood and like… quite a lot has happened in my family lately, which also affected me, as well as talking about a bit of everything but also about the stress and… so we've had great conversations.
>
> (I8.5)

Based on the trustful conversations with the school nurse the adolescents learned to verbalize their emotions instead of "shutting them in" and "bottling them up," which developed their ability to understand bodily sensations, thoughts, and feelings as meaningful information and to learn strategies for dealing with them. In addition, the continuity enhanced the trustful relationship, as the follow-up dialogues with the school nurse were important for making progress visible to the adolescents, thus motivating them to continue.

> Although I didn't know that I made progress like that… so with a headache especially, I would not have managed it. And then just uh, like this, was really shocked (laughs). Because I thought that these conversations won't really do much and I have… I think it's a little bit because you… you need to realize that you're stressed too, instead of… I don't know (laughs). You kind of need to…well, as I said, get a grip on your problems.
>
> (I7)

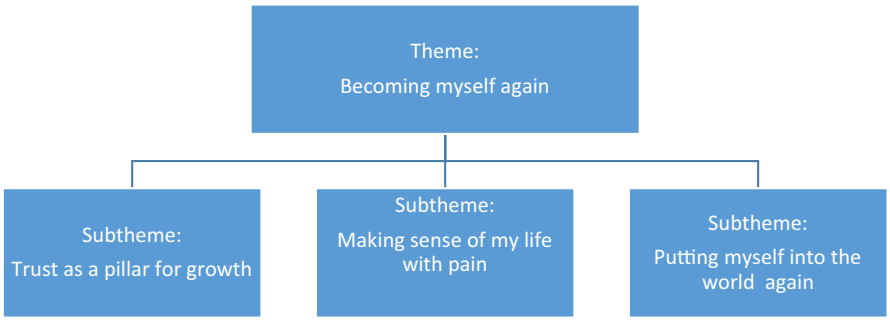

FIGURE 1 The figure reflects a schematic view over the overarching theme and sub-themes.

4.1.2 | Sub-theme: Making sense of my life with pain

For the adolescents in the present study, feeling different and alone with their pain problems was a central aspect of their stress. Nevertheless, they stated that the feeling of loneliness changed through increased awareness of pain, such as that it is a common problem and that other people have similar problems. The combination of education and person-centered support in interpreting the information they received, helped them to make sense of a previously chaotic existence.

> Yes, because I think it's good that they understand it, and when I kind of wonder why it hurts in waves like that, she explains a bit about it and so on. Like unanswered questions, as well as her answering stuff like that, which I didn't think she would, which I thought you had to look up yourself. Because you can find a lot of rubbish online, and it feels good to go to her and talk.
>
> (I19.4)

The added value of learning by doing is emphasized in the narratives. By using body-oriented aspects such as relaxation, breathing exercises, and physical activity, the adolescents learned to better understand the causes and effects of chronic pain and associated problems. This can be interpreted as trust in the body, which further boosted their confidence in their own abilities and strengthened their self-confidence.

> So, I didn't think that just going and talking to someone would help my head… the headache or stomach ache or something. But I thought, sure, I'll go and talk to someone, but my stress will still be there. And of course, it can still stress me out, but now I have control so that… so it was beyond my expectations. I thought I would walk around and be just as stressed and that it would affect my schoolwork, but it's going so damned well for me in school right now, excuse the swearing (laughs).
>
> (I3.9)

4.1.3 | Sub-theme: Putting myself out into the world again

Once they had made sense of their inner world with pain, which was characterized by pain and associated problems, they were ready to move into the outside world again. They described how through a combination of conversation, education, and bodily techniques, they could focus on their needs and boundaries in relation to themselves as well as in relation to others, thus creating conditions for change and the ability to influence their own situation. They had learned new ways of thinking that were perceived as helpful in managing and reducing stress, pain, anxiety, worry, and sleep disorders.

> I have shut myself off and not been social and I have not… talked to anyone… It's almost a bit painful if you turn yourself off because then the rest of the body shuts off. It doesn't feel emotions and it isn't as social as it needs to be. So, I think that you shouldn't, as it were, shut yourself off from the world continue to fight through it as if you're looking ahead and not standing still or looking back. You can take it very slowly, but you're still moving forward so you aren't standing still. You kind of take it at your own pace.
>
> (I7.10)

The adolescents experienced an improvement in their ability to handle their problems and communicate about them with their parents, teachers, and friends. They perceived it as having led to increased commitment and support from the surrounding environment compared to before the intervention when they felt alone with their problems and situation. Hence it was valuable to have come to the realization that they were actually not alone. Some adolescents said they had learned to pursue constructive relationships and to withdraw from destructive ones, which helped improve both their mood and their school performance. The adolescents were also able to give increased support to friends with similar problems and encourage them, for example, to approach the school nurse for help.

The adolescents realized that assuming personal responsibility was central to action, which motivated them to change. There would be no resolution to their problems if they did not address them themselves. For example, they might use this insight to tackle schoolwork and complete tasks straight away instead of postponing them. By realizing the importance of assuming personal responsibility and using tools to manage their pain, they were able to opt to stay in school instead of going home due to pain. The adolescents described that finding greater confidence in their ability to influence their problems and mood also increased their confidence in themselves as a person.

> But then it's going really well for me at school right now. And it's a real relief that I've found out what it is. Everything feels… so…everything feels, kind of much clearer. I feel so much more, how should I say, I feel healthier and I feel more… pure or whatever, that I am me.
>
> (I3.10)

5 | DISCUSSION

In this empirical study, the adolescents' experiences of the HOPE intervention were characterized by a trust-building process that

strengthened their personal identities as a basic prerequisite for change.

The interviews aimed to further explore the adolescents' views on the HOPE intervention and thereby gain more in-depth knowledge about PCC for future interventions. Trust was identified as crucial for the adolescents in the present study. According to Smirnova and Owens, there are three levels of trust: self-trust, interpersonal, and institutional trust.[30] According to the adolescents, HOPE strengthened their trust on two of the three levels: self-trust and interpersonal trust in relation to the school nurse, parents, friends, and teachers. To our knowledge, trust as perceived by adolescents with chronic pain is poorly understood. Trust is a complex phenomenon, which is difficult to measure and operationalize, but low trust in the healthcare system has been found to be associated with poor self-reported health in a sample of 28 000 respondents (18–60 years) in the Region Skåne in the South of Sweden.[31] Currently, no such studies have been performed on adolescents, but it is reasonable to believe that a similar pattern exists. In adults, trust in doctors and medicine is associated with better treatment adherence and clinical outcomes.[32] Even more interesting is the fact that self-efficacy has been suggested to mediate the outcome. It would be valuable to further investigate how trust in school nurses and other healthcare professionals is associated with self-efficacy and health in adolescents with chronic pain.

As mentioned in the introduction, our HOPE intervention was found to have a significant effect on self-efficacy in the sub-group of adolescents attending secondary school.[18] This is in line with other studies on adults with chronic pain, in which patients' self-efficacy was strengthened when staff applied a person-centred approach.[33] In the present study, we were curious to understand the essence of self-efficacy as perceived by the adolescents. In their narratives, they expressed the importance of assuming personal responsibility for bringing about change in relation to discomfort, while well-being was something they became aware of during the intervention. They highlighted the fact that they did not only develop their self-confidence but also their ability to accept and feel that they are just as valuable even if they fail—in other words, their self-compassion was promoted. According to Neff,[34] accepting one's own worth even when one fails is a sign of self-compassion. In the sense of compassion being directed toward oneself as a person, having an empathetic view of one's failures and shortcomings as well as accepting them as part of being human. Neff also believes this can be a strategy for regulating and sharing emotions with others, thus enhancing our ability to become closer to each other.[34] An accepting attitude toward one's shortcomings can be a valuable asset during the vulnerable years of adolescence[35] when the basis for future mental health is created.[36]

The value of using bodily-oriented strategies has been emphasized in our study. Other studies have evaluated the effect of bodily-oriented interventions in adolescents with chronic pain. Duberg et al.[37] showed that a dance intervention focusing on joy of movement as opposed to performance for girls with internalized problems, such as psychosomatic pain and mental ill-health, improved their self-rated health more than that of the control group at all follow-ups. In a subsequent interview study, Duberg et al.,[38] reported that the adolescents experienced that the intervention increased their self-trust. The adolescents in Duberg's study were also recruited from school healthcare, but the study did not explicitly include a person-centered approach. Neto et al. explored adolescents' experiences of undergoing a pain education intervention with psychoeducational aspects in combination with exercise.[39] According to the adolescents in Neto et al.,[39] the intervention contributed to facilitating the reconceptualization of pain as a complement to exercise. It was also highlighted that the psychoeducational intervention had a positive effect on self-efficacy.[39] We argue that combining a physically active intervention with a person-centred approach and adding an evidence-based pain education, could enable even more adolescents with chronic pain to improve their health. Another interesting reflection is that the majority of participants in HOPE were girls, as was also the case in Duberg et al.'s studies.[37,38] The research field needs to investigate and develop active person-centred interventions that attract boys.

Our results also highlight the relevance of managing pain in order to function socially. Other studies discuss the link between chronic pain and social functioning in adolescents. For example, in one interview study, adolescents described that chronic pain impacted on their social functioning leading to isolation, and difficulties interacting with others and socializing with friends, thus generating a need to develop social affirmation and belonging.[36] Another interview study on 16 adolescents who experienced chronic pain, also found that the participants expressed concern about being different and not accepted by peers, that their opportunities for romantic relationships could be affected, and that they may not be considered worthy as friends in the long term. All but one of the adolescents in that study preferred not to share their problems with others in order to maintain the perception of those around them that they were normal.[40]

5.1 | Strengths and limitations

We argue that the overarching strength of this study is that we managed to create a trustful atmosphere, thus making the participants willing to share their narratives. Participants were recruited through strategic selection in order to cover both public and private schools in two regions of varying socioeconomic contexts. Another strength is that an accurate description of the selection, participants, data collection, and analysis have been provided so that the reader can assess the transferability of the study.

There are also some limitations. The recruitment was affected and possibly prolonged, as the schools from which the adolescents were recruited needed to focus on taking care of the large numbers of adolescents who came to Sweden as refugees rather than participating in a study with adolescents on chronic pain. As data were collected in two regions in Sweden, the results may not be representative of other regions in Sweden or in other countries.

Another limitation may be that the majority of participants were girls, hence affecting the possibility to generalize the results to boys.

6 | CONCLUSION

A person-centred intervention such as HOPE applied in a school context is promising for promoting confidence in adolescents with chronic pain. A trust-building process emerged, in terms of both the adolescents' trust in the healthcare staff they meet and their confidence in their own ability to handle and influence their situation, which in the long term can promote trust in themselves as a person.

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DATA AVAILABILITY STATEMENT

Data are available on request due to privacy/ethical restrictions.

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