

Giving Voice to Young People: Evocative Autoethnography as a Method of Researching Personal Experiences Connected to Adolescent Idiopathic Scoliosis. A discursive article

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DOI: <https://doi.org/10.5114/phr.2023.123329>

Received: 22.07.2022 **Reviewed:** 01.09.2022 **Accepted:** 08.09.2022

Abstract

Background: Adolescent idiopathic scoliosis (AIS) is one of the most common spine disorders amongst young people, with a rich body of biomedical research mainly focused on the effects of interventions. However, there still needs to be more research regarding personal experiences connected to this complex health condition, including people's views, preferences, or attitudes, even though they constitute evidence-based practice and person-centred care as understood today. This work aims to present that addressing this serious evidence-to-practice gap is needed and possible via qualitative research, specifically evocative autoethnography.

Materials and methods: Evocative autoethnography will thus be introduced, described, and reviewed in terms of its usefulness in AIS research, discussing two autoethnographies addressing and based upon scoliosis experiences of the first author of this work, that can serve as examples of how this method can be utilised.

Results and conclusions: Evocative autoethnography allows analysing and often exploring such important issues related to AIS as body image, emotional difficulties, or psychological distress, informing health care professionals and rehabilitation practice. This is especially important in the field of AIS, where the personal consequences, coping with the condition, as well as a choice of treatment adherence are often profound and challenging for the patients and their families.

Key words

scoliosis, autoethnography, adolescents, evidence-based practice, personal experience, qualitative research.

Introduction

This article will focus on qualitative research, evocative autoethnography in particular, as a valuable method of researching and exploring personal experiences connected to adolescent idiopathic scoliosis (AIS). This health condition is, on the one hand, one of the most common spine disorders affecting around 0.47-5.2% of young people [1], but on the other – it also seems under-researched in terms of exploring and analysing adolescent experiences connected to it [2,3].

AIS research has been dominated by quantitative studies, presenting mostly bio-medical and expert perspectives [2-6]. The vast majority of studies in the field of scoliosis focus on screening, diagnostics, and ways of treatment [2,5-7] – analysing measurable outcomes, such as Cobb angles of spine curvature, which of course, is necessary to ascertain the most effective ways of dealing with scoliosis-related health issues.

However, what is missing from current research is a personal – or we can say – insider perspective, presenting and exploring experiences of people actually touched by this condition [3,7]. This includes young people diagnosed with it, their family members, medical practitioners, and others potentially involved [7]. In addition, not much is known about the personal dimension and the psychosocial perspective – including, but not limited to, emotional issues, body image issues, or psychological issues connected to self-esteem, self-acceptance, or the fear of being rejected by others [3,8].

This seems extraordinary because seeking patient perspectives – their views, preferences, and attitudes – is currently a crucial part of person-centred care as well as the evolved paradigm of evidence-based practice [9-11]. A person-centred approach, including patients' involvement and consultation as experts in their medical care [12], as well as shared decision-making, are landmarks of contemporary healthcare policy and practice [13,14]. In the context of research and study designs, it is also where the distinction be-

tween quantitative and qualitative research is.

The aim of this article is, thus, to underline and express the crucial need for qualitative studies – focused on individual experiences, views, and voices rather than on “outcome studies” or “descriptive studies” – focused on facts and figures, data, findings and effects of interventions, in the subject matter of scoliosis in its personal dimension of young people.

The particular focus here will be on evocative autoethnography, which will be introduced and described in terms of its applicability in scoliosis research, presenting two example papers describing, exploring, and based upon scoliosis experiences of the first author of this work [15,16].

To better introduce the subject matter, specifically the method, we will apply the autoethnography style of reporting, described as the autoethnographic language: a living, accessible, narrative first-person language, as it is used in evocative autoethnographies [17,18]. This is employed to follow the perspective of personal experience of writing autoethnography, exposing the different approaches it utilises and brings to the phenomena under study, as well as to demonstrate its specificity of reporting. In the sections of this article presenting autoethnographic experiences, the appropriate first-person singular language forms will be used when talking from or about the personal experience because they concern the first author (WG). In the remaining sections, the first-person plural forms will be used, which refers to all the co-authors.

Materials and methods

Autoethnography – a methodological introduction

Writing about autoethnography is challenging because there is no single autoethnography [18-21]. Quite the opposite: there are variations and different understandings of it, with applications and connections to different research practices. Autoethnography can be a process and a product

[22]; it can be a research technique, a methodology, or a wholly new research paradigm [21-23]. What various kinds of autoethnography do have in common, however, is that the researchers write in the first person, focusing on their personal lived experiences and connecting them to broader social and (sub-) cultural contexts [22,24]. Whether the personal story and experiences are emphasised, or the sociological lenses and analysis in connection to culture are prioritised also varies depending on the approach taken and the research questions being explored [20,21].

Early autoethnographic forms were born out of the qualitative research development from the postmodern and experimental phase into the post-experimental phase at the end of the last century. This is when numerous publications appeared in scientific journals, including method-specific periodicals such as the "Journal of Contemporary Ethnography", "Qualitative Research", and "Qualitative Inquiry" [25].

Before these vital developments, however, qualitative research went through a critical period of change and growth in pursuing new perspectives. This, coming back to autoethnography, was connected to the crisis of representation [22]. This crisis concerned themes and subjects from the human experience that the existing positivist research methodologies were unable to present and analyse in a wide-ranging and comprehensive manner. Those human matters were put in a "subjective", "emotional", or "biased" box, as referred to in the positivist perspective [22]. However, research topics used in these studies are part of human life and are often culturally and socially complex, difficult, and vital to people experiencing them. Living with a diagnosis of a certain condition, illness or disability involves developing new embodied practices, changes in social identities (e.g. healthy, ill, with disability), emotional and mental states, and social (e.g. family, professional) roles. Moreover, it not only changes a person's life but also influences their existing social relations and the lives of their family and friends [3].

This was also connected to the more general trend in both the scientific world and, more widely, the Western world, to focus more on individual life stories and bring personal experiences into the light [21].

Autoethnographers use various data collection techniques, for instance (but not limited to) interviews, personal journals, (self-) observations, artefacts, reflective accounts, and visual reports. They also vary in data presentation and analysis approaches. Thus, there is no one prescription for autoethnography, as it is not only a scientific but also a literary form of narrative writing used to represent certain aspects of human life, which is a complex, layered, fragmented, contradictory, and inconsistent process [20-22]. Hence, autoethnographic accounts are also diverse and unique.

In recent decades, there has been a growing interest in autoethnography, especially in the fields of health, pedagogy, education, art, marketing, anthropology, and communication studies [22,25-27].

The two main types are analytic and evocative autoethnographies. Each is rooted in different research traditions, requires a different definition of the researcher, explores different research questions, and serves different aims, depending on the topic under investigation.

Concerning the experiences of persons diagnosed with scoliosis, applying evocative autoethnography appears more useful and justified. This particular approach is the main focus of this paper, as in this form, bodily experiences, sensations, feelings, practices, actions, and emotions are vital and are not used for theoretical generalisation. They are not treated in a research-centred way, i.e., to emphasise methodological criteria, but are necessary layers of stories and issues under study. Hence, this methodological inclusion can help uncover aspects that are often tacit at first and difficult to name and help make the non-verbal more expressed and understood. This is crucial, especially in the research on adolescent experiences related to AIS.

Results

Personal experiences connected to scoliosis

When researching the field of scoliosis alongside creating the two autoethnographies, we were astounded by how very little we could uncover about other people's experiences related to their scoliosis [28-30]. Recently, some studies have appeared to take on this subject, mostly connected to experiences of scoliosis surgery [31,32] and brace treatment [33]. However, when it comes to the question of how "it feels to be the subject of screening, diagnosing and treatment of AIS" [15] (p. 2) – still very little has been published [2,7] even though there are calls for the inclusion of qualitative studies to complement and broaden the understanding of scoliosis [34]. On the contrary, many personal accounts and experiences are shared via blogs, websites, or social media – where young people with scoliosis can freely express themselves, all of which are still not currently recognised as sources of scientific evidence [7,35]. There have been some movements in the literature to start using these sources of experience for medical practitioners to learn more about their patients [36,37].

There are many difficult decisions that patients and their family members need to make after the diagnosis of AIS is given, such as, amongst others, whether to "wait and see" or – choose active treatment. If so, what kind of treatment will be most effective and least invasive, especially since treatment adherence is an issue in scoliosis patients [38]. Therefore, the process of informed decision-making should take into consideration young people's needs, views, feelings, and experiences:

"Adolescents, who are in a liminal stage between childhood and adulthood, are often excluded from decision-making. (...) Attending to the power dynamics at work in determining who can participate and under what conditions is key to understanding adolescents' agency and capabilities." [39] (p. 2)

Research shows that around 32% of adolescents diagnosed with AIS experience emotional distress [40]. This further highlights the need for young people with AIS to be actively included in scoliosis research to enable the exploration of the emotional dimension of scoliosis.

Thus, to give a voice to young people, they should be engaged as active participants in research, also seeking research methods that will enable them to fully affirm and gain insights into their experiences. Autoethnography can be used as an innovative method to allow insider perspectives into adolescent experiences. Moreover, it can also help to bridge the gap – between anecdotal, purely personal writing, and strictly biomedical quantitative studies, allowing to encompass a wide range of culturally contextualised experiences.

Autoethnography about the scoliosis experiences

When I, the first author of this work, was twelve years old, I was diagnosed with AIS. This was a turning point in my life, influencing me and my perceptions of my body in many ways. In my twenties, I finally discovered autoethnography as a research method that enabled me to explore and make sense of those complex experiences. Those autoethnographies present and analyse my adolescent experiences connected to scoliosis diagnosis [15], as well as finding my own ways of coping and healing from scoliosis-related bodily doubt [16].

For me, working on autoethnographies connected to scoliosis experiences turned out to be transformative for five main reasons: 1) It gave voice to my adolescent self who, at the time, felt powerless and scared; 2) It helped me to make sense of my experiences in the wider cultural context; 3) It enable me to share with the wider community to seek their experiences; 4) It allowed me to express my views on the need for changes in this area; and 5) It assisted me in finding personal healing.

Giving voice to my adolescent self

Autoethnographies are frequently occupied with processes and events in human life that are often hidden, marginalised, or suppressed. They allow one to express their voice through the inclusion of an individual's inner psychological processes, emotional states, and spiritual dimensions so that the unseen can become more visible [25]. Additionally, by including my memories, bodily states, reflections, journal entries, artefacts, and embodied writing, I was able to make explicit what I felt I went through as a young person and how, in my view, this has affected me and my life.

For many years I have felt that my experiences connected to scoliosis, even though they had a huge impact on me personally, were generally silent – nobody knew about what was happening in my inner adolescent world, especially the doctors and other practitioners involved. Creating the two autoethnographies about experiencing scoliosis diagnosis, medical encounters, and exercise treatments, as well as finding my own ways of coping and healing through conscious movement practices, allowed me to express my views and make my voice heard.

As a researcher, I felt I had been attempting to speak on behalf of myself and, potentially, of other repressed voices, often excluded from the mainstream narrative.

Making sense of my experiences in the wider cultural context

Autoethnographies also deconstruct, analyse and/or comment on cultural practices [25]. Through working on my autoethnographies, I realised fully that my experiences did not (and do not) exist in a vacuum but are part of a bigger picture – of cultural, social, and biographical contexts.

This enriched my perspective: as an adolescent going through the emotionally painful, embarrassing, derived privacy scoliosis screening, I felt this very strongly as an attack on me and my integrity as a young human being. However, through colliding my experiences with literature,

I was able to gain cultural awareness of the processes I endured, especially the screening and diagnosis process, which are not only medical but also cultural practices and have been developed because of multiple historical and cultural influences. As we wrote in "The end of being a straight child (...)" autoethnography:

“Calling for a “correct” posture is calling for a posture that is perfect and unattainable. The screenings evolved from “measuring unclad bodies with the use of wall charts, graphs, plumb lines, silhouettes, and, most frequently, photographs.” [15] (p. 609)

We demonstrate that the way of looking at bodies in biomedical procedures and research is often perfectionist and aesthetically driven. The spine is examined in terms of geometrical symmetry, objectifying the body [15]. However, the body is also a subject – a living body with a plethora of inner processes. Thus, writing autoethnography can also assist in building a personal narrative and re-discovering a sense of subjective agency.

Sharing with the wider community

What was especially important to me when researching others' experiences was also becoming truly aware that I was not isolated in this condition and that so many other young people all over the world go through their own experiences connected to scoliosis. So I am part of a bigger social entity. Furthermore, that also gave me a sense of relief and more motivation to seek what others' experiences are so that our, perhaps different, voices can be heard. Thus, autoethnography is also an invitation to other people affected in some way by scoliosis to share their stories.

Discussion

The Need for Changes

The evocation element was vital in the two presented autoethnographies. I felt it essential for the medical practitioners involved in scoliosis care to get a glimpse of what it might be like to be going through the processes of screening, treat-

ment, and – afterwards – finding ways of healing and coping; to invite them "to feel emotional resonance" [22] (p. 307) with me. To gain this insider perspective alongside their objective view. It seemed that they felt no concern for my needs and experience of care. However, in countries like England, the US and Australia, patients are increasingly being asked for their views and experiences via patient-reported experience and outcome measures (PREMs and PROMs): tools used for monitoring patients' health and experience, as well as for improving their health outcomes [41]. Hence, healthcare systems are gradually developing to be more person-centred; however, as pointed out by Bull and Callander, there is still some way to go internationally in this respect [41], and – especially children and families should be more involved in ensuring their active engagement in care [42]. Some changes in these scoliosis processes are needed.

What I realised through my autoethnographic work was that the changes I would have liked to have seen as a young person were connected to transforming the whole experience to what is now known in research as person-centred. For instance, I would have liked to have been treated with more respect and dignity during both the screening and the medical visits, which, in my case, always required me to be nearly undressed. In addition, I would have chosen to have been informed and educated regarding the complexity of AIS in terms of its severity, natural history, and progression. Additionally, I would have preferred to have been communicated with and not only talked about but at the least asked about my needs, views, and preferences [15,16]. Importantly, especially during the vulnerable time of puberty, I also needed emotional support around all of the uncertainties and difficult experiences connected to scoliosis.

Another aspect of change that is essential and well-known within the scoliosis literature is patient adherence (and acceptance) to various types of treatment, such as braces or so-called

corrective exercises, which seem to be difficult for young people to adhere to [33,38]. My experiences connected to corrective exercises were negative, I felt stigmatised because of them, and as a result, I was adamant not to participate. In contrast to this, whilst under the care of a chiropractor, I felt I was treated as an individual. He was able to create a meaningful relationship with me and took enough time to communicate, explain and teach me exercises that would increase my body awareness and which could be done in the privacy of my own home. This process initiated independent adherence to regular exercises brought about by a more person-centred approach [15].

Thus, through autoethnographic work, we can begin to explore what is important to young people when it comes to treatment, how they can be supported regarding their specific needs, the impact this has on adherence, and what potentially hinders this process.

Finding Personal Healing

Evocative autoethnography can also serve a therapeutic function [20,25]. Many autoethnographies present and/or analyse difficult or even traumatic events from the writer-researchers lives [18,22,25]. This process can be tremendously painful but, at the same time, presents the opportunity to work through the suffering, a healing act in itself [18].

In my case, presenting ways of coping and healing was the subject of the second autoethnography [16]. The self-reflective writing and situating my experiences in the broader context turned out to be a therapeutic undertaking for me. I was given the opportunity to identify and make sense of my paths to healing, form a narrative, use reflective thinking and delve deep into experiences and memories. Through writing, I was able to find out that my career choices and movement practices were also directed by the need for personal healing which could then be analysed. Hence, through the autoethnographic research process,

tacit knowledge could become known and expressed, allowing for interpretation [25].

Autoethnography also serves a semiotic function related to the power of language in constructing social reality and personal identity [25]. Through writing about one's experiences, it is possible to create new meanings about past events, phenomena, and the world. To me, this was especially important, as medical language surrounding scoliosis sounded very negative and even scary to me, with words such as "deformity" or "hump" [15,16] adding to my distress at the time.

The diagnosis of scoliosis was the beginning of the development of my personal bodily doubt [16] and the initiation of my search for adaptive coping strategies in response, learning to trust my body again. This healing process was possible for me through engaging in somatic movement practices, which allowed me to re-experience my body as an object – a moving, living body with inner life and processes. It enabled me to find support and acceptance within myself again. Writing autoethnography was an important part of this, as it allowed me to reinforce the feeling of being a subject and to have a sense of agency and active involvement in my healing.

Just as conscious movement practices bring insights about the body and build bodily awareness, so the autoethnographic process can help to develop self-awareness. For me, movement and writing, this place of meeting between body and mind, were both equally necessary in the therapeutic process.

As a creative, analytical practice [22], autoethnography invites people who engage in it to include their bodily experiences, embodiment practices, and emotional expressions. This can be experienced through reflective writing and – in further autoethnographic forms – poetry, art, or dance [22], which can be especially valuable with this particular age group, as puberty is a unique time in a person's life and development. Autoethnography can equally serve as an accessible and

diverse way of allowing self-expression for adolescents, addressing and validating their emotional needs.

Importantly, evocative autoethnography, a potentially therapeutic form of writing, can be part of the personal healing process through the autoethnographic approach of self-reflection and self-expression.

Thus, the writer-researcher gains greater self-awareness, making sense of their experiences. This assists in the development of self-responsibility for one's own health and self-care in young people through engaging with inner dialogue and exploring questions such as "What do I feel?", "What do I need?", "What am I scared of?".

Crucially, the readers of autoethnographies are then invited to get a glimpse into the writer's inner world. This is useful for others diagnosed with scoliosis – as a means of sharing with the wider community. Additionally, it also allows physicians, physiotherapists, nurses, family members, and researchers to immerse themselves in a person's life experience, fully witnessing what these people are going through. This, in turn, may lead to the presentation of medical practices as cultural and to the evolution of scoliosis treatment to become more adolescent-aware and person-centred.

Conclusions

Autoethnography is a research approach that has the potential to broaden the understanding and knowledge of a wide variety of issues around scoliosis, including the dimension of the personal or subjective experiences of young people, as well as those closest to them. This includes their views and preferences – of which so little has been published so far.

Novel research methods are needed to gradually begin to fill this fundamental research-to-practice gap in the management of scoliosis. Evocative autoethnography seems an indispensable

option as one of such methods, allowing for new, innovative research methods with young people. Moreover, it has the potential to give young people a voice and, through that – to allow them to engage in their own healthcare, feeling part of the informed decision-making process.

By providing further insights into the body of knowledge and understanding the experiences of adolescents from their perspectives, autoethnography should contribute to re-examining existing scoliosis practices from screening, through diagnosis, to treatment options, as well as research priorities.

Conflicts of interest

The authors declare no conflict of interest.

Funding statement

The authors did not receive funding for the work reported in this manuscript.

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