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Kristina Amja, Marie Vigouroux, Gillian Newman et Richard B. Hovey

Volume 9, numéro 1, 2022

Congress October 2021

URI : <https://id.erudit.org/iderudit/1085638ar>

DOI : <https://doi.org/10.26443/ijwpc.v9i1.316>

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Éditeur(s)

McGill University Library

ISSN

2291-918X (numérique)

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Citer ce document

Amja, K., Vigouroux, M., Newman, G. & Hovey, R. (2022). The lived experiences of teenage girls with scoliosis and the effect of a peer support group, Curvy Girls. *The International Journal of Whole Person Care*, 9(1), 2–3. <https://doi.org/10.26443/ijwpc.v9i1.316>

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THE LIVED EXPERIENCES OF TEENAGE GIRLS LIVING WITH SCOLIOSIS AND THE EFFECT OF A PEER SUPPORT GROUP, CURVY GIRLS

Kristina Amja^{1*}, Marie Vigouroux¹, Gillian Newman², Richard B. Hovey¹

1* Corresponding Author: Faculty of Dental Medicine and Oral Health Sciences, McGill University, Montreal, Quebec, Canada

kristina.amja@mail.mcgill.ca

2 Curvy Girls Scoliosis Support Group, Toronto, Ontario, Canada

Keywords: Scoliosis, Peer Support, Teenage Girls

CONTEXT: Scoliosis is an abnormal lateral curvature of the spinal column and affects approximately 1% to 3% of adolescents. The relationship between pain and idiopathic scoliosis has not been well documented and remains unclear in the literature. Curvy Girls is an international peer-run support group that aims to reduce scoliosis's emotional impact through education, mutual support, and self-empowerment.

OBJECTIVES: This study endeavors (1) to gain insight into the lived experience of teenage girls living with scoliosis and (2) to understand how the peer support group, Curvy Girls, has impacted their lives.

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APPROACH: We interviewed sixteen members of Curvy Girls living with scoliosis. The interviews were transcribed verbatim, and then interpreted using applied philosophical hermeneutics.

FINDINGS:

I. Personal Lens: The narratives of living with undiagnosed pain revealed confusion, solitude, and loneliness. The impact of labeling the pain (i.e., an official diagnosis) led to relief in some cases or irritation in some other cases.

II. Healthcare Lens: The stories of negative healthcare experiences and their impact on teenage girls are uncovered. The teenage girls wanted to be included in treatment decisions that may endorse autonomy and independence during adolescence.

III. Peer support Lens: Curvy Girls provides a safe environment for these adolescent girls to engage. The power of sharing and communicating helps Curvy Girls members cope and feel a sense of belonging.

SIGNIFICANCE: An insight into these teenage girls' lived experiences allows for a better understanding of living with scoliosis and how a peer support group can help with this journey. ■