

The role of medical students in advocacy for rare diseases – Experience from a Low- and Middle-Income Country (LMIC)



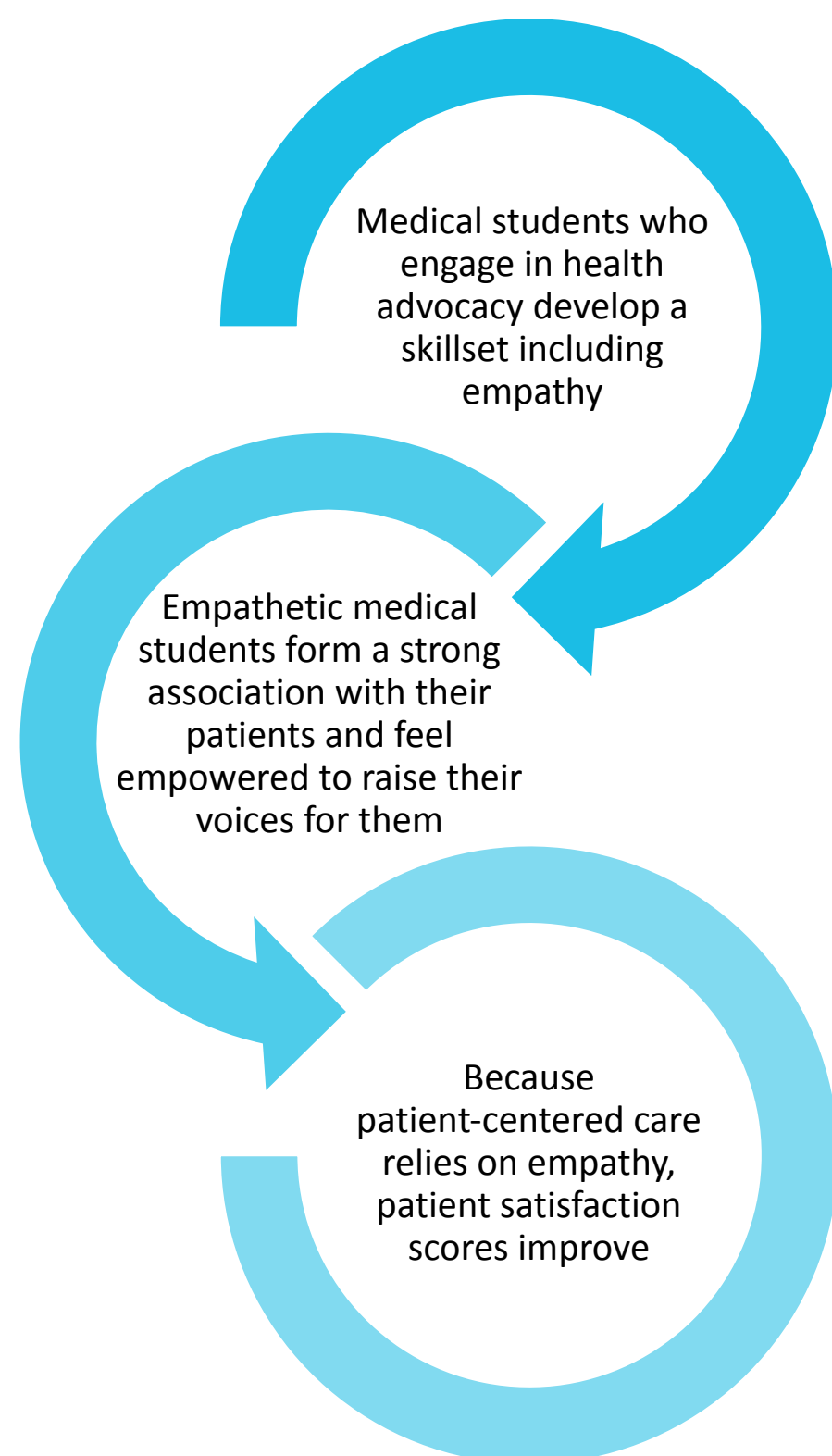
THE AGA KHAN UNIVERSITY

Javeria Bilal Qamar, Muhammad Uzair, Shahnour Ahmed, Hamna Ganny, Lena Jafri, Salman Kirmani

Introduction

- Everyone living with a rare disease makes up a total of over 300 million people worldwide.
- We share experiences from Pakistan of medical students spearheading one such effort as stakeholders in the care for rare.
- We also discuss the importance of teaching health advocacy as part of the medical education framework, helping nurture empathy in medical students.

Teaching health advocacy as part of the medical education framework



How we advocated for rare diseases at AKUH

Social Media Visibility – infographics viewed by over 800 young adults and medical students

Launch of Newborn Screening Program for Selected Inherited Metabolic Disorders, with over 100 faculty members

4 individuals with rare diseases invited to share their experiences in a panel-discussion-like-format to an audience of 26 medical students

What did we learn from the conversations?

- Rare disease diagnostic journeys are exhausting
- Challenges included the psychological impact of receiving a diagnosis and the pain of dealing with something no one around them was dealing with
- Inequity in available opportunities becoming more apparent as they age, and the support that rare-disease community groups offered
- Medical students have a great role to play as health care providers of the future by helping individuals feel included, seen, understood and accepted

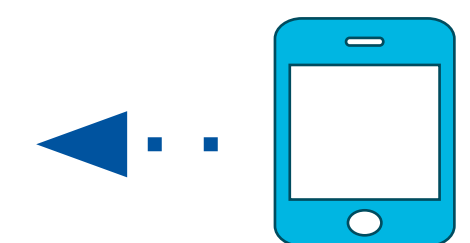
Future Implications

- Since individual institutions in Islamabad, Peshawar and Karachi [20,21,22] are already observing this day and engaging in awareness programs and workshops independently, the possibility for multi-center collaborations exists.
- Studies demonstrate a need to increase awareness about rare diseases amongst medical students [23,24] This gap can be filled through regular events, or by incorporating this in the medical curriculum itself.

Key Messages

'It is imperative that all of us have the capacity to be able to see them in the same light that those with rare diseases see themselves'

- Having a rare disease and living in a developing country like Pakistan predisposes those with rare diseases to many challenges.
- Individuals with rare diseases are experts in their diseases [18] and there is much that we can learn from them to tailor the care we provide according to their needs
- Evidence based advocacy by these future physicians will mean that they understand the dynamics of policy making and are able to successfully maneuver their way to a favorable position for their patients and the community



Scan the code to download the full paper

Acknowledgements

We appreciate all members of Pediatrics for Life (PFL) Student Interest Group at the Aga Khan University for volunteering their time and energy to advocate for Rare Diseases.

References

- [9] T.D. Bhat, L.C. Loh, Building a generation of physician advocates: Acad. Med. 90 (12) (2015)
- [18] A.T. Mccray, K. Leblanc, Diseases Network U, Patients as partners in rare disease diagnosis and research, Yale J. Biol. Med. 94 (2021)
- [23] J. Domaradzki, D. Walkowiak, Medical students' knowledge and opinions about rare diseases. Rare Dis. Res. 8 (4) (2019)
- [24] D. Walkowiak, K. Bokayeva, A. Miraleyeva, J. Domaradzki, The awareness of rare diseases among medical students and practicing physicians in the Republic of Kazakhstan. Front. Public Health (2022)

