



Solutions Group 3

S4CCC Guideline Series:

INTEGRATING PSYCHOSOCIAL CARE ACROSS CLEFT SPECIALITIES

Propelling Learning Through Collaborative Research
May 2023



CONTEXT

What is “Psychosocial Care”?

Psychosocial refers to “an individual’s social, cognitive, and psychological development in interaction with their environment”. Psychosocial care is support given to help meet the mental, emotional, social, and spiritual needs of patients with cleft and their families.

Why is psychosocial care important to LMIC CCC teams?

Studies suggest that persons with cleft are likely to be viewed differently and may experience social impediments. Individuals with cleft often have some form of facial anomaly or scar which may limit their social interaction and may prevent them from reaching their full potential.

Unhelpful beliefs about cleft in some LMIC contexts may represent an additional limitation to be overcome. Furthermore, families may experience difficulty in accepting their child in light of community stigma about their baby’s condition.

How did we develop these recommendations?

A diverse group of 11 cleft professionals participated in a 3-month research ‘sprint’ that included a global survey that was completed by 130 cleft professionals from 39 countries. These recommendations were presented and discussed at the March 2023 S4CCC Conference.

RECOMMENDATION

#1



Improve Awareness of Cleft Stigma and Community Knowledge about Cleft



Rationale

Cleft conditions may not be widely understood in many Lower Middle Income Country (LMIC) contexts. The prevalence of stigma and myths about cleft can delay or discourage families from seeking treatment. Social stigma can also create tension between parents and limit the self-esteem of patients themselves.

Raising awareness about cleft can take the form of social media posts, radio advertisements, community outreach, and visiting schools to work with teachers and fellow students of a patient.

Cleft community awareness initiatives and cleft-informed psychosocial care for patients and families are strategies that can helpfully build upon one another.



"Some parents believe cleft is God's way for punishing them for whatever they did." (Malaysian respondent)

"People come for surgery before marriage and expect improvement in their speech." (Indian respondent)



RECOMMENDATION

#2



Offer psychosocial training to the whole cleft team



Rationale

Every member of the team can benefit from standardized training by a psychosocial professional using an evidence-informed approach. This training should incorporate a focus upon specific roles, defined responsibilities and clear lines of communication within the team.

Publicizing the integrality of psychosocial care within cleft treatment helps to limit community prejudice about accessing this type of support. Psychosocial care also promotes patient acceptance of cleft care plans, reduces risks of abandoning treatment, and limits unnecessary procedures.

Common psychosocial practice standards within CCC teams ensures that psychosocial care is valued for its contribution to improving outcomes, assuring a better quality of life for patients.



61% of LMIC survey respondents pointed to inadequate information/training about psychosocial care.



RECOMMENDATION

#3



Advocate for increased psychosocial care support for patients and families.



Rationale

Hospital management and community leaders must 'buy-in' to the benefit of psychosocial care and bolster its provision. Local government, private and NGO funders can enable the expansion of psychosocial support to patients and families by providing funding for both staff training and the expansion of psychosocial services.

Academic literature highlighting the relevance and importance of psychosocial care may be a useful tool to onboard management and to advocate with funders.



"I think administrators and funders need to be more aware of the need for psychosocial care. Good patient outcomes depend on more than just successful surgery, speech, and teeth."

(Respondent from Australia)

"Funding is not available for psychosocial care in resource limited settings." (Respondent from Kenya)



RECOMMENDATION

#4



Engage in psychosocial research & development



Rationale

A lot of work is still to be done in identifying gaps in LMIC patient care to move toward an evidence-informed approach. We are confident that sharing contemporary psychosocial cleft research will generate greater support for psychosocial care and to improve the quality of the treatment provided.

Creating, translating, validating and employing psychosocial screening tools will contribute to the evidence base.

Additionally, identifying linkages between a cleft team's existing tools for assessing outcomes and psychosocial tools will facilitate the training of clinicians. Some tools are currently limited to one discipline or region of the world but they may have applicability in other fields or regions.



The survey revealed that there are not any standardised psychosocial screening tools, nor standardised training commonly available for cleft psychosocial care in LMIC contexts.





NEXT STEPS

The Roundtable made it clear that effective psychosocial care requires a team effort. Having a single practitioner working in a silo should not be any team's goal. Psychosocial care should motivate parents and patients to adhere to treatment, attend, and actively participate in their appointments.

Psychosocial care begins with parents as early as the cleft is detected and continues throughout treatment. The choice of words and actions by clinicians from the moment of birth is a component of psychosocial care. Psychosocial care both reduces unnecessary surgeries and contributes to the effectiveness of care plans.

This document is intended to provide recommendations that facilitate psychosocial integration into team based cleft care. It can serve as a starting point for discussions within your team, with hospital management, or with funders

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Additional Resources

Click to access the following

[Strategies to Integrate Psychosocial Care](#)
[Improving the Quality of Psychosocial Care](#)
[Facilitating Positive Psychosocial Outcomes](#)
[Upskilling Psychological Care](#)
[Assessing Psychosocial Care and Appearance](#)
[Solutions Group 3 Roundtable Discussion](#)

