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Bridging Care Beyond Cure: Psychosocial Rehabilitation for children and youth with Life-Threatening Illnesses

Abstract

Children and adolescents with life-threatening illnesses often face multifaceted difficulties not only in physical health, but also in their emotional, social, and functional well-being. While medical systems focus on symptom management, Rehabilitation care offers a unique opportunity to address these deeper psychosocial needs through versatile and integrated care models. This study evaluates the impact of Happy Feet Home (HFH), a palliative day-care centre in Mumbai, which provides a restorative journey of care spanning hospital support, day-care engagement, and community-based psychosocial rehabilitation. Anchored in a biopsychosocial and empowerment framework. The study adopts a mixed-methods longitudinal design with youth aged 8–21 years mixed-methods design was employed with 72 participants assessed on the Quality-of-Life Scale (QOLS; 16 items) and 69 participants on the Rosenberg Self-Esteem Scale (RSES). Descriptive statistics summarized scores, while qualitative data from semi-structured interviews and focus groups were thematically analysed. Data were collected at three points: (1) hospital entry, (2) transition into HFH day-care services, and (3) engagement with community-based support. Quantitative findings showed high levels of self-esteem (M = 24.49, SD = 3.82) and generally elevated QoL scores (M = 79.73, SD = 37.38), with most participants clustered at the upper range (96–110). A small subset reported lower QoL, reflecting acute distress or complex care needs. Qualitative analysis revealed themes of emotional regulation and expression, peer connection and relational safety, agency through creative and vocational engagement, and expressive arts as healing. Additional themes of hope, gratitude, and symbolic rebirth highlighted how participants re-authored their narratives of illness and trauma. Caregivers reported greater relational safety, openness, and hope as outcomes of HFH's holistic model. Findings contribute to understanding the role of versatile, holistic care frameworks in improving quality of life for young individuals with critical illnesses, underscoring the need for policy recognition and replication of such models in diverse care settings.

Research Article

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Introduction

Adolescence is a critical period marked by pivotal physical, cognitive, and emotional development. When compounded by a life-threatening illness, these developmental milestones are often severely disrupted; adolescents may struggle with diminished autonomy, purpose, and identity, and confront heightened psychological distress [1]. Children's evolving cognitive abilities may lead to existential distress and fears about death compounded by caregivers' and professionals' discomfort in discussing prognosis [2]. This emotional burden often manifests as heightened anxiety and reduced emotional well-being. Such psychological impacts underscore the inadequacy of purely symptom-based approaches.

A scoping review revealed that adolescents and young adults with advanced illness experience a complex mix of physical symptom burden and psychological challenges, yet tailored palliative care services remain limited especially in low- and middle-income countries [1]. Quality of life (QoL) in this population is frequently compromised, with anxiety, depression, social isolation, and schooling disruption commonly reported [1]. The concept of total pain incorporating physical, emotional, social, and spiritual suffering is well established in palliative care, underscoring the need for holistic interventions (source derived from standard palliative care frameworks). Based on these estimates, each year in the world, around 63 children out of 100,000 population under 15 years old will require palliative care at the end of life. Diseases which require palliative care for children include cancer, cardiovascular diseases, cirrhosis of the liver, congenital anomalies, blood and immune disorders, HIV/AIDS, meningitis, kidney diseases, neurological disorders and neonatal conditions. The World Health Organisation stated that in Indonesia, the mortality rate for children aged 5–14 in 2016 was 5.3 (probability of dying per 1000 children). The number of deaths for children under-five was 131,000, infant deaths numbered 110,000 and neonatal deaths 68,000 [3].

Pediatric palliative care itself is designed to address suffering in its full complexity, offering family- and developmentally centred support that includes symptom management, psychosocial therapies, and coordinated care. Evidence suggests that early integration of such care can enhance overall QoL, reduce unnecessary hospital utilization, and contribute to resilience and hope, particularly in resource-constrained settings where disease burden is high [1].

In India, the landscape of paediatric palliative care has expanded through pioneering organizations like Happy Feet Home (HFH). In India, the landscape of paediatric palliative care has expanded through pioneering organizations like Happy Feet Home (HFH). Founded in 2014 as India's one of the initial palliative care centre – HFH offers free holistic and comprehensive support that spans across hospital outreach, day care services and community engagement through various services like educational, vocational, medical, psychosocial and nutritional support. HFH serves children and youth with life threatening and life limiting conditions such as HIV, cancer and Thalassemia. Combining psychosocial interventions, creative expression, life skills coaching and therapeutic engagement across hospitals and community settings this model exemplifies a biopsychosocial and empowerment-oriented continuum of care.

Despite notable gains, [4] note that pressing challenges such as obesity, physical inactivity, substance misuse, and inequalities continue to threaten adolescent well-being. They advocate for the application of prevention science and positive youth development frameworks to address these multifaceted issues. In this respect, the integrative, empowerment-based model of care at Happy Feet Home (HFH) in Mumbai resonates strongly with the principles outlined in their work. HFH's blend of psychosocial therapy, life-skills training, and community-based recreational and vocational activities operationalizes the call for multi-setting, holistic interventions. By providing adolescents with both supportive relationships and meaningful opportunities for self-expression and growth, HFH illustrates how evidence-informed rehabilitation psychology can enhance quality of life and resilience among youth facing life-threatening illnesses.

Aim of the Study

Guided by a biopsychosocial and empowerment framework, this study investigates the effectiveness of HFH's restorative care model in enhancing quality of life and self-esteem among youth aged 8–21 years with life-threatening illnesses. Using a mixed-methods longitudinal design, the research quantifies changes in QoL using validated scales and explores lived experiences through semi-structured interviews and focus group discussions.

Objectives

1. To evaluate changes in Quality of Life (QoL) among children and adolescents engaged in all three HFH programs i.e. hospital outreach, day-care services, and community-based interventions.
2. To assess Self-Esteem specifically among children enrolled in the day-care program, given its intensive and comprehensive psychosocial interventions.
3. To examine qualitative experiences of participants regarding emotional regulation, resilience, and social connectedness through HFH's interventions.

Methodology

Research Design

This study adopted a mixed-methods design to evaluate psychosocial outcomes among children and adolescents with life-threatening illnesses enrolled at Happy Feet Home (HFH), a palliative day-care centre in Mumbai. A combination of quantitative and qualitative approaches was employed to capture both measurable changes in quality of life (QoL) and self-esteem, as well as the lived experiences of participants. Mixed-methods research is particularly suitable for rehabilitation psychology as it integrates statistical analysis with subjective narratives, thereby providing a richer understanding of interventions and outcomes [5].

Note: The study has been in work since the past 2 years (2023 – onwards). The beneficiaries have been associated with the organisation and its interventions at different point in time. Most of them are associated for more than 2 / 3 years.

Participants

A purposive sample of 72 participants aged 8 to 21 years was recruited from the HFH program. Eligibility criteria included (a) medical diagnosis of a life-threatening or life-limiting illness (e.g., HIV, thalassemia, cancer), (b) enrolment at HFH for a minimum of three months, and (c) ability to provide informed assent/consent with caregiver approval. Caregivers were also engaged as secondary informants during the qualitative phase.

Quantitative Measures

Two standardized instruments were used:

1. Quality of Life Scale (QOLS; 16-item version): This measure assesses subjective satisfaction across domains such as health, relationships, independence, work, learning, and creative expression. Each item is scored on a 7-point Likert scale (1 = extremely dissatisfied to 7 = extremely satisfied), with total scores ranging from 16 to 112; higher scores indicate greater life satisfaction [6].

2. Rosenberg Self-Esteem Scale (RSES): A widely validated 10-item measure of global self-esteem, using a 4-point Likert scale ranging from strongly agree to strongly disagree. Scores range from 0–30, with higher scores reflecting higher self-esteem [7].

Note: The Quality of Life Scale (QOLS; 16-item version) was administered to all participants, as it captures broad psychosocial well-being across care settings. The Rosenberg Self-Esteem Scale (RSES) was administered only to participants enrolled in the day-care program (n = 69), where children receive the most intensive and structured psychosocial interventions. This decision was based on the program's therapeutic depth, which was expected to have the most direct impact on self-esteem outcomes.

Both instruments were administered at baseline (hospital entry or early enrollment) and at follow-up points after day-care engagement and community participation.

Qualitative Measures

To complement quantitative findings, semi-structured interviews and focus group discussions were conducted with participants and caregivers. The interview guide explored domains of emotional regulation, resilience, peer relationships, educational and vocational aspirations, and experiences of HFH interventions (e.g., group therapy, life-skills training, recreational activities such as dance, cricket, capoeira, and vocational classes). Each interview lasted approximately 30–40 minutes and was audio-recorded with consent.

Procedure

Data collection followed a sequential explanatory design. Quantitative data were collected first to establish baseline outcomes, followed by qualitative interviews to deepen understanding of participants' experiences and explain patterns observed in the statistical results. Ethical clearance was obtained from an institutional ethics committee. Informed consent from caregivers and assent from children were ensured, with confidentiality maintained throughout.

Data Analysis

Quantitative data were analysed using descriptive and correlational statistics. All analyses were conducted in Microsoft Excel and SPSS.

- **Data preparation:**
    - Raw scores from the Quality of Life Scale (QOLS; 16-item version) and Rosenberg Self-Esteem Scale (RSES) were checked for completeness, plausibility, and outliers.

- Missing or extreme invalid responses were excluded from analysis.

- **Descriptive analysis:**
  - For both QOLS and RSES, means, standard deviations, medians, and ranges were calculated to describe central tendency and variability.
  - Frequency distributions were computed to examine how many participants fell into high, moderate, or low scoring ranges.
  - Graphical representations (bar charts, histograms, boxplots) were created to visualize the distribution of scores.

- **Qualitative Analysis:** Interview and focus group transcripts were analysed thematically using Braun and Clarke's (2006) six-phase framework. Themes related to resilience, emotional expression, peer connection, and empowerment were identified. Triangulation with quantitative results was used to strengthen validity.

Results

Quantitative Findings



Fig 1: Mean Scores of Participants for (QOLS & RSES)

As seen in fig 1, total of 72 participants completed the Quality of Life Scale (QOLS; 16 items). Scores ranged from 0 to 110, with a mean score of 79.73 (SD = 37.38). The median score was 96, and most participants clustered at the upper end (96–110), indicating strong perceived quality of life. However, a small number of children reported extremely low scores, reflecting acute medical or psychosocial distress.

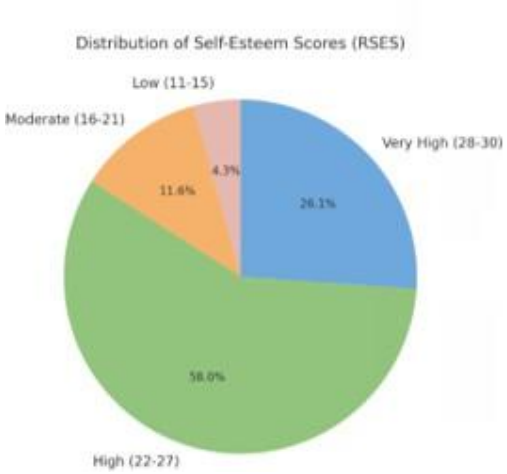


Fig 2: Distribution of Self Esteem Scores

Self-esteem was measured for 69 participants, primarily those receiving more intensive medical or psychosocial care. As seen in Fig.2, The Rosenberg Self-Esteem Scale (RSES) showed scores ranging from 11 to 30, with a mean of 24.49 (SD = 3.82) and a median of 25. The majority of participants scored between 22 and 27, suggesting generally strong levels of self-esteem.

Qualitative Findings

Semi-structured interviews and focus group discussions highlighted several key themes:

- **Emotional regulation and expression**

Children and adolescents reported increased ability to name emotions and express themselves safely. Through art, movement, and group sharing, participants described feeling "lighter" and "more in control." Caregivers noted fewer episodes of withdrawal and anger outbursts, highlighting improved emotional regulation.

- **Peer connection and relational safety**

HFH was consistently described as "a place where we feel understood." Group activities and shared creative practices cultivated a sense of trust, belonging, and mutual support. Participants often spoke of forming friendships that provided safety and solidarity, reducing feelings of isolation.

- **Agency through creative and vocational engagement**

Engagement in capoeira, skating, cricket, dance, and vocational courses fostered self-confidence and future orientation. For many, learning new skills represented the possibility of independence, dignity, and personal growth beyond illness.

- **Expressive arts as healing**

Activities such as visual journaling, painting, storytelling, and collaborative art provided safe avenues to externalize pain and reconstruct meaning. Participants emphasized how art "helped me say what I couldn't in words" and allowed them to reclaim authorship of their narratives.

- **Caregiver perspectives**

Families observed increased hope, improved communication, and relational warmth at home. Many reported feelings reassured by HFH's holistic support, describing it as "a second family" that nurtured both children and caregivers.

- **Hope and gratitude**

A recurring theme was a sense of gratitude for life and the opportunities provided through HFH. Participants articulated appreciation for small joys, friendships, and the ability to imagine futures once thought impossible. One adolescent reflected: "I feel thankful every day that I can still dream and smile." Gratitude became a protective resource that buffered despair and reinforced resilience.

- **New life and rebirth**

For some, HFH represented a symbolic rebirth a space to shed old burdens and begin anew. Through art and narrative exercises, participants frequently employed imagery of flowers blooming, phoenixes rising, or new paths opening. These metaphors signified the reclaiming of agency and identity after periods of silence and shame.

Discussion

The findings suggest that Happy Feet Home (HFH) has a significant positive impact on both the quality of life and self-esteem of children and adolescents with life-threatening illnesses. Quantitatively, the high QOLS scores reflect strong social and functional well-being, despite the challenges of chronic illness. The consistently elevated self-esteem scores indicate that participants retained a sense of self-worth, resilience, and agency, even in the face of medical adversity. These results align with prior literature demonstrating that integrative palliative care approaches improve both psychosocial functioning and perceived life quality [8,9].

The variability observed in QOLS, with a few children scoring extremely low, highlights the heterogeneity of experiences in palliative care. These outliers may represent children in acute stages of illness or those lacking stable family support. Such cases underscore the need for targeted psychosocial interventions alongside broader community-based supports, a point emphasized in palliative care research in low- and middle-income countries [1].

Qualitatively, the findings provide depth to the numerical outcomes. Expressive arts emerged as a critical vehicle for healing, offering symbolic distance and creative re-authoring of trauma narratives. This resonates with [10] observation that art engages non-verbal memory and supports trauma integration. Group work, meanwhile, helped address the relational ruptures that accompany trauma and illness, fostering co-regulation and belonging. These outcomes mirror [11] emphasis on the protective role of peer connection in adolescent health.

Vocational and recreational activities further enhanced self-esteem by promoting mastery, skill acquisition, and future orientation. Caregiver perspectives highlight that HFH's model not only impacts children but also strengthens family systems, aligning with [12] ecological framework of development.

Overall, the combination of high QoL and self-esteem scores with rich qualitative themes suggests that HFH's biopsychosocial and empowerment-based framework is effective in addressing both internal psychological resources and external quality of life.

Limitations

First, the sample size was modest (N = 72 for QoL and N = 69 for self-esteem), which restricts the generalizability of the findings to wider populations of children with life-threatening illnesses. Second, due to programmatic reasons, not all participants were assessed on both measures, resulting in limited overlap (n = 3), which

precluded meaningful correlation analysis between quality of life and self-esteem. Third, the clustering of scores at the higher end of both scales suggests a possible ceiling effect, limiting the sensitivity of these measures to capture subtle variations in psychosocial outcomes. Fourth, the quantitative design was cross-sectional rather than longitudinal, which prevents strong causal inferences about the impact of HFH interventions over time. Fifth, qualitative data, while rich, may have been influenced by social desirability bias, particularly in group settings where participants may have emphasized positive experiences. Finally, the study's context-specific nature focused on a single palliative care center in Mumbai, limits the transferability of findings to other cultural or institutional contexts.

Recommendations

Based on these findings and limitations, several recommendations emerge for future research and practice:

1. Larger, multi-site studies are recommended to increase the generalizability of findings and compare outcomes across different care contexts in India and other low- and middle-income countries.
2. Longitudinal research designs should be employed to capture changes in quality of life and self-esteem over time, as well as the sustainability of psychosocial gains.
3. Mixed-methods triangulation can be strengthened by ensuring more participants are assessed on both QoL and self-esteem measures, allowing for robust correlation and regression analyses.
4. To address measurement limitations, future studies could complement QOLS and RSES with additional scales that are less prone to ceiling effects or that measure domains such as resilience, hope, or meaning-making.
5. Cultural adaptation of expressive arts and narrative practices should be expanded, ensuring approaches remain sensitive to South Asian contexts where family honor, silence, and collectivist norms influence disclosure and healing.
6. Capacity building for caregivers and families should be integrated as a formal component of palliative care programs, as caregiver well-being directly influences children's psychosocial outcomes.
7. Policy makers and practitioners should recognize and scale up community-based models like HFH, embedding expressive arts, vocational activities, and peer support as essential not supplementary elements of pediatric palliative care.

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APPENDIX A: Qualitative Interview Guide

Note: The following semi-structured interview guide was used during one-on-one sessions with children and young people at Hope for Healing (HFH). Questions were used flexibly to facilitate open dialogue and adapt to the participants' age and developmental stage.

1. Expression & Communication:

- Can you share how you usually express your feelings here at HFH (e.g., through words, art, movement, or other ways)?

2. Peer Relationships & Social Dynamics:

- What has it been like to spend time with other children or young people at HFH? How have friendships or group activities influenced you?

3. Self-Concept & Identity:

- When you think about yourself now compared to before joining HFH, what changes do you notice in how you feel about yourself?

4. Future Outlook & Hope:

- Are there things you now feel hopeful or excited about for the future? Can you describe them?

5. Creative & Expressive Therapies:

- How has drawing, painting, dance, or other creative activities helped you in expressing yourself or dealing with difficult emotions?

6. Resilience & Empowerment:

- Can you share a moment when you felt stronger or more capable of handling challenges because of your time here?

7. Family & Caregiver Dynamics:

- Have you noticed any changes in your relationship with your family or caregivers since coming to HFH?

8. Overall Synthesis / Symbolic Reflection:

- If you had to describe what HFH means to you in one story, image, or symbol, what would it be?

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