

An Assessment Of Distress in a Chronic Illness Population Living in a Community Setting Affected by Fragility, Conflict and Vulnerability.

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Background

Rural communities with both host and refugee populations which are also impacted by conflict, multiple levels of fragility including economic, climatic and political exposes them to vulnerability and marginalisation. Access to palliative care for both host and refugee communities in such settings is often poor and causes of distress complex. In Adjumani and Obongi districts, Uganda where at least 50% of the population have experienced forced displacement due to conflict from South Sudan. A previous context and needs analysis revealed significant trauma, and mental health challenges. For this new assessment tools were chosen to assess distress as alongside palliative care need.

Aim

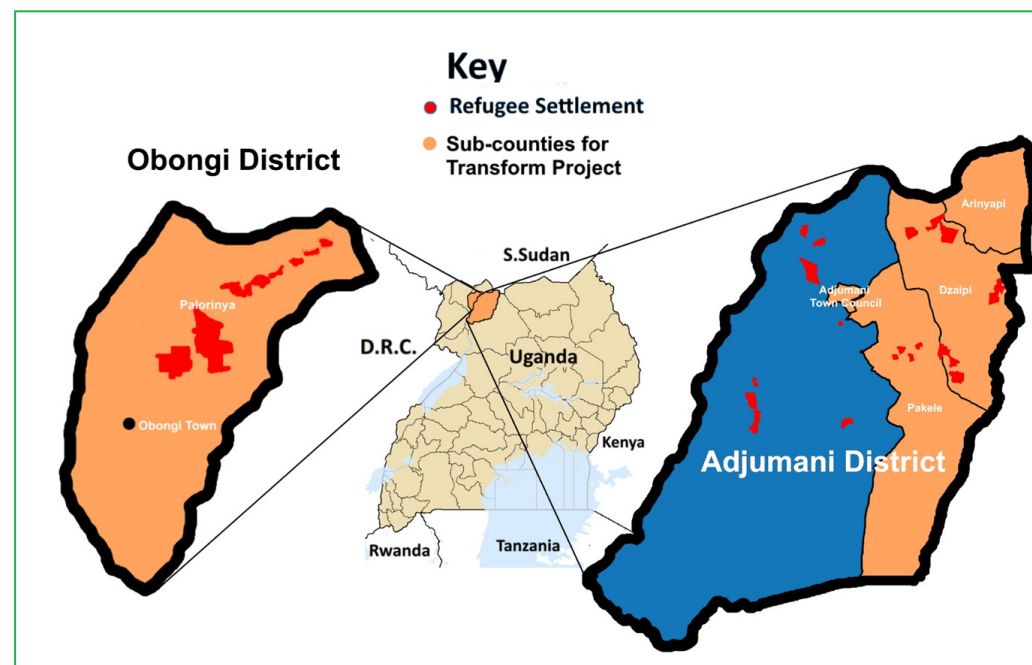
To assess distress alongside palliative care needs of patients with chronic illness in host and refugee communities.

Methods

Following ethical approval community health workers were trained to identify children (over 8 years) and adults with serious chronic illness. Assent (8-18) and consent 18+ was gained, before participating in a home-based screening for eligibility then surveyed using the following tools - ECOG, IPOS or CPOS, Distress Thermometer and DASS21 (adults) administered by experienced and bilingual researchers. Demographic data was collected.

Results

322 patients completed the study and reported acceptability for the process; females (57.1%) males (42.9%), median age 40.0 years range 8 to 97 years. Ugandan (54.0%), South Sudanese (43.8%), Sudanese (2.2%). 58.4% eat once a day or less. 86.4% have no formal or primary only education. 92.4% scored 5 or above with the Distress Thermometer indicating moderate or severe distress. Significant associations between distress and variables such as anxiety, depression, pain, mobility, access to information, education and wealth. Spearman's Correlation between DASS 21 and Distress thermometer shows positive association for anxiety 0.422 and depression 0.32.



Social Demographics

Participants: **322**

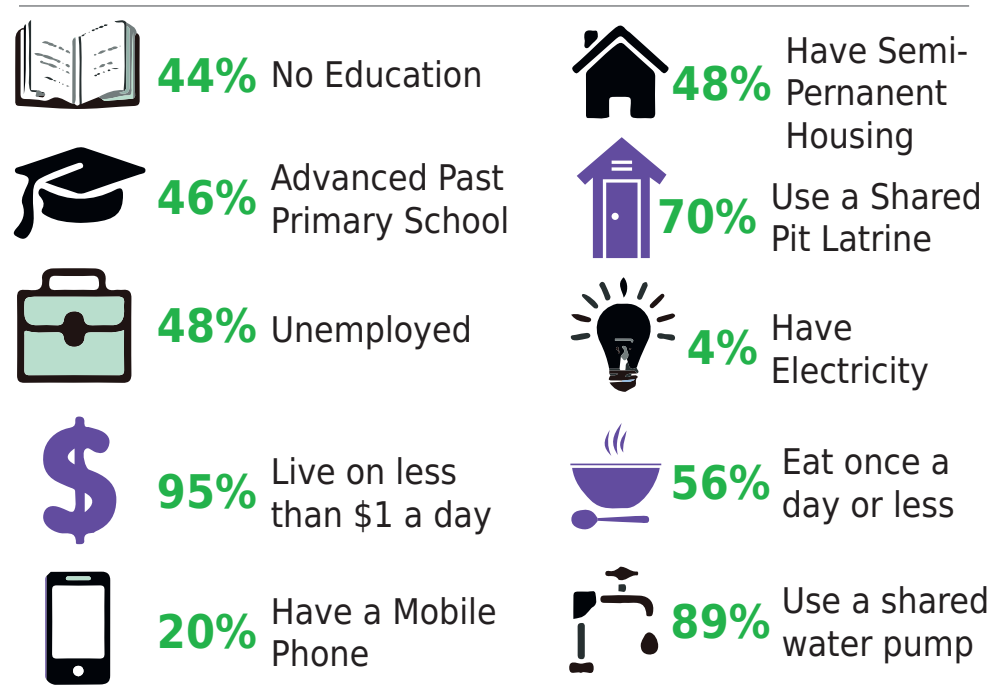
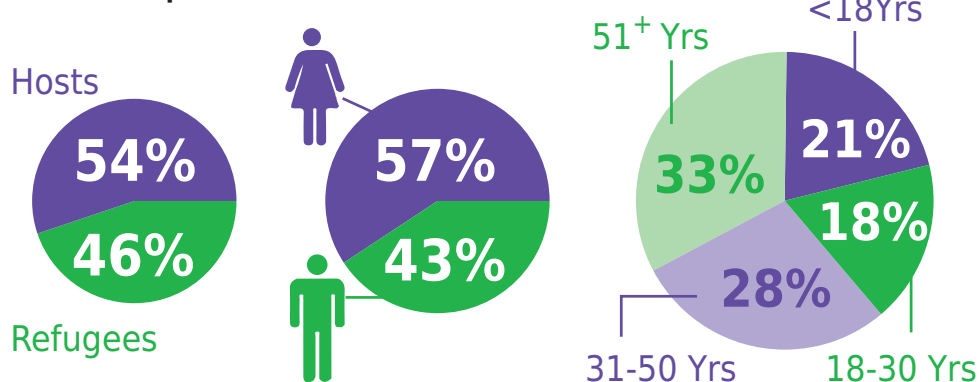
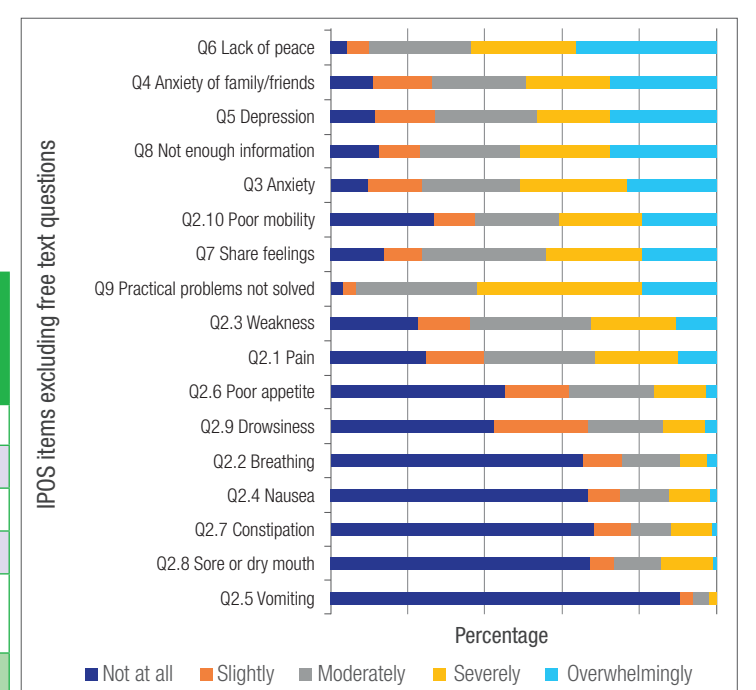
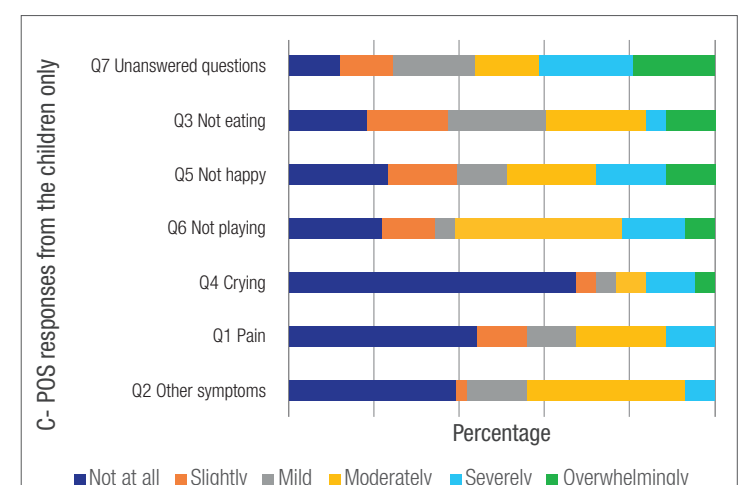
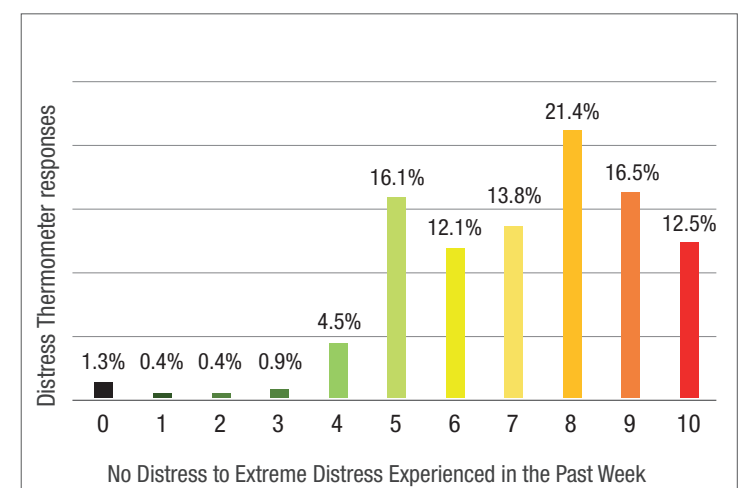


Table 1.0 Overall, Spearman's Correlation between DASS 21 and Distress Thermometer			
	Depression	Anxiety	Stress
Depression	-		
Anxiety	0.572***	-	
Stress	0.531***	0.631***	-
Distress Thermometer	0.323***	0.422***	0.232**

Note. *p<.05, **p<.01, ***p<.001

Table 2.0 Overall, Spearman's Correlation between DASS 21 and Distress Thermometer - Refugees			
	Depression	Anxiety	Stress
Depression	-		
Anxiety	0.595***	-	
Stress	0.550***	0.622***	-
Distress Thermometer	0.230*	0.488***	0.285*

Note. *p<.05, **p<.01, ***p<.001



Discussion

Distress is a valuable paradigm for approaching complex palliative care and trauma needs. IPOS and the Distress Thermometer provided screening assessments that could be used to identify those needing further assessment and referral. While the Distress Thermometer captured overlapping emotional dimensions with the DASS-21 subscales, particularly with Depression and Anxiety, it remains a distinct measure of distress. The moderate to weak correlations with DASS-21 subscales suggest it might be tapping into unique aspects of psychological distress not fully captured by the DASS-21, making it a complementary tool for assessing emotional well-being. Further work is needed to determine the place for these tools, to align with qualitative data and to compare with standard palliative care and psychiatric assessment.