Children with cerebral palsy in Ghana: malnutrition, feeding challenges and caregiver quality of life

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Abstract

Aim: To assess feeding difficulties and nutritional status among children with cerebral palsy in Ghana, and assess whether severity of feeding difficulties and malnutrition are independently associated with caregiver quality of life.

Methods: This cross-sectional survey included 76 children with cerebral palsy (18 months to 12 years) from four regions of Ghana. Severity of cerebral palsy was classified using the Gross Motor Function Classification System and anthropometric measures were taken. Caregivers rated their quality of life (PedsQL™Family Impact questionnaire Module) and difficulties with eight aspects of child feeding. Logistic regression analysis explored factors (socio-economic characteristics, severity of cerebral palsy and feeding difficulties) associated with being underweight. Linear regression was undertaken to assess the relationship between caregiver quality of life and child malnutrition and feeding difficulties.

Results. Poor nutritional status was common:: 65% of children aged <5 years were categorised as underweight, 54% as stunted and 58% as wasted. Reported difficulties with child's feeding were common and was associated with the child being underweight (Odds Ratio 10.7 95% CI 2.3-49.6) and poorer caregiver quality of life (p<0.001). No association between caregiver quality of life and nutritional status was evident.

Interpretation: Among rural, low resource populations in Ghana, there is a need for appropriate, accessible caregiver training and support around feeding practises of their children with cerebral palsy, to improve child nutritional status and caregiver well-being.
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What this paper adds:

- Malnutrition is very common among children with cerebral palsy in this rural population in Ghana.
- Feeding difficulties in this population were strongly associated with being underweight
- Feeding difficulties were associated with poorer caregiver quality of life
- Child nutritional status was not associated with caregiver quality of life

Cerebral palsy is a common cause of physical disability in children[1] and evidence suggests that children with cerebral palsy are particularly vulnerable to malnutrition.[2] Reasons for this include physiological factors such as dysregulation of growth hormone secretion and muscle spasticity.[3] Feeding difficulties, including oral-motor impairments affecting chewing, food ingestion and self-feeding, are common and often severe. [4, 5] These difficulties may negatively impact the responsiveness of caregiver feeding practises, further reducing nutritional intake.[6] At the same time, malnutrition may exacerbate physical and cognitive functional limitations among children with cerebral palsy through reduced muscle strength, lower immunity and cerebral development and other negative impacts on general health.[7, 8] The right to food is enshrined into various Human Rights charters, however the nutritional needs of children with disabilities are rarely addressed.[9] In rural, low resource settings additional challenges around poor availability of food and nutrition services are likely to be common. However, there is limited empirical information on the feeding and nutritional status and risk factors for malnutrition among children with cerebral palsy in these settings, including in Ghana This information is important for informing policies, programmes and evidence based advocacy for children with cerebral palsy and their families.

As well as increasing the risk of malnutrition, , child feeding difficulties may negatively impact caregiver well-being.[10] Research has highlighted negative experiences and stress associated, for example, with drooling, choking and the high level of assistance required to support children with cerebral palsy.[10, 11] However, while there is good theoretical rationale for an association, few studies have specifically explored the impact of feeding difficulties in children with cerebral palsy on caregiver quality of life particularly in rural low income settings. It has been postulated that caregiver's recognition of their child being underweight may, itself, cause stress affecting quality of life.[12] However, the independent relationship between malnutrition and caregiver QoL has not been well explored. This deserves attention in terms of the delivery and impact of appropriate interventions supporting both children with cerebral palsy and their caregivers.

The objectives of this study were to i) estimate the prevalence of malnutrition and describe the feeding difficulties experienced by children with cerebral palsy in rural Ghana, ii) assess possible risk factors for malnutrition in this population and iii) assess whether feeding difficulties and nutritional status are independently associated with caregiver quality of life

Methods

This article reports on a survey conducted as part of an evaluation to assess the impact of a caregiver training programme for carers of children with cerebral palsy. More details on this programme and the evaluation are available in an online study report. [13] The study was conducted in eight sites across four regions in Ghana: Upper East (northern Ghana), Greater Accra, Brong Ahafo and Ashanti (southern Ghana) regions.

Study participants

The study population included caregivers and children with cerebral palsy who were identified for inclusion in the caregiver training programmes in eight different communities. They were primarily recruited from the community through databases of local Community Based Rehabilitation programmes in these (n=46), as well as additional case finding through community leaders, mothers attending existing support groups and other key informants (n=8). In addition, the records of physiotherapists from Agogo Presbyterian Hospital were reviewed and all children who had been diagnosed within the last 6 months and who had received less than two physiotherapy sessions were recruited (n=22). Cerebral palsy was identified as a diagnosis by a qualified clinician (developmental paediatrician or physiotherapist). Eligibility criteria to the training programme and research study were confirmed diagnosis of cerebral palsy and age 18 months-12 years. This is the target age group for the caregiver training programme. Children may have had some previous physiotherapy but caregivers were excluded if they were already a member of a parent support group. The target for the evaluation study was to include eight training groups of 8-10 parents: recruitment efforts continued at each site until this size was reached. Each caregiver was invited to participate in the parent training programme as well as this research project. The data presented here were collected in May-June 2015, before the caregiver training programme was initiated.

Data collection

A structured questionnaire was used to collect data on the children (demographics, severity of cerebral palsy, feeding difficulties, reported health status and anthropometry) and their primary caregivers (socio-demographic and economic characteristics and quality of life). Data were collected by two interviewers who underwent three days of training. The questionnaire was pilot tested and verbally translated into three local languages.

Severity of cerebral palsy was assessed using the Gross Motor Function Classification System. [14] To assess feeding difficulties, caregivers were asked to rate how often their child experienced

difficulties with eight different domains of feeding (such as choking, eating enough) using a 5-point response scale ranging from 'never' to 'always'. These questions were adapted from a previous study of children with cerebral palsy in Bangladesh. [10]

Caregiver and family quality of life (QoL) was assessed using the 36-item PedsQL™Family Impact questionnaire Module[15] which includes six sub-scales: self-reported physical, emotional, social, and cognitive functioning, communication and family, daily activities and family relationships. The scale was translated into the three local languages following PedsQL linguistic validation guidelines.[16]

To assess for malnutrition, anthropometric measures were taken using standardised protocols adapted for use in the field. Where possible, standing height was measured for children > 5 years and recumbent length was taken for children <5 years, both measured to nearest 0.1cm. Knee height[17] (CLPR65 Anthropometric Caliper, MediForm, Oregon, USA) was recorded for all children to the nearest 0.1cm. Following WHO best-practice procedures[18], height, length, and knee height measurements were obtained twice by two independent observers: the average was taken as the final measurement if they agreed to within <0.5cm, else both re-measured until agreement was achieved. Mid Upper Arm Circumference (MUAC) was recorded for all children (mm gradation MUAC tape, Teaching Aids at Low Cost, TALC). We recorded weight to the nearest 0.1kg. Children who could not stand independently were first weighed together with their caregiver and then the weight of the caregiver alone was subtracted.

Statistical Analysis

We re-grouped GMFCS levels for analysis as follows: mild (levels 1 and II), moderate (levels III) and severe (levels IV and V). A composite feeding score was calculated from the eight feeding questions and divided into tertiles (least difficulties, middle and greatest difficulties) for analysis. We assessed the internal consistency of this score by calculating Cronbach's alpha coefficients and item-total correlations. Principal components analysis was used to derive a socio-economic status (SES) index from poverty indicators including household building materials and asset ownership. The SES index was divided into tertiles for analysis.

Knee height was used as a proxy measure for children whose standing height (n=16) or recumbent height (n=3) were unobtainable. Knee height and laying length were plotted on a scatter graph and the line of best fit was used to predict missing height data. This approach was used in the absence of

a validated method for converting knee height to standing height for children with cerebral palsy. The Emergency Nutrition Assessment[19] and WHO Anthroplus software were used to calculate weight-for-age, height-for-age and weight-for-height z scores according to WHO growth standards. Children were considered to have malnutrition if they had z scores between -2 and -3 and severe malnutrition if they had z scores <3 years.[20]. The definition of wasting using MUAC was 115mm – 124mm and severe wasting as <115mm. Children with z-score values outside of the recommended range (>5 or 6 or < -5 or -6, depending on the measure) were excluded from the analysis as per standard guidelines – these being more likely due to error than real extreme values (n=6). [21]

Total and sub-scale PedsQL scores (calculated as the sum of the items over the number of items answered) were converted into scores out of 100.[15] We used the total scale score for analyses.

Multivariate logistic regression was undertaken to explore factors (socio-economic characteristics, severity of cerebral palsy and feeding difficulties) associated with being underweight. Underweight (defined for this analysis as weight-for-age z score <2) was selected as the anthropometric indicator because it was considered the most robust measure, taking into account the difficulties measuring height for some children in this study population. Further this has been identified in previous research as being better predictor of mortality among children with cerebral palsy compared to stunting and wasting.[22] Multivariate linear regression was used to explore the relationship between caregiver QoL with child malnutrition and feeding difficulties, adjusted for potential confounders (caregiver and child age, SES, region and cerebral palsy severity). For these analyses, QoL life data were transformed because the data were skewed. Square root transformation was selected as, using the 'ladder' command in Stata, this was found to best resemble a normal distribution. With consideration to the number of variables under study, we used p<0.01 as our cut-off for statistical significance.

Ethical Considerations

Ethical approval was granted from ethics committees of London School of Hygiene and Tropical Medicine and The Noguchi Memorial Institute for Medical Research, College of Health Sciences, University of Ghana. Informed written or thumb-printed consent was sought from caregivers prior to data collection. All children with moderate or severe malnutrition were referred for follow up.

Results

Study population characteristics

Data were collected on 76 of the 77 children invited to participate (response rate 98%) (table 1). The majority of children were under 5 years (72%) and mean age was 3.8 years (95% CI 3.2- 4.5). There were 47% females in the sample. The majority of children had severe cerebral palsy: 25% were classified as having GMFCS level V, 28% with level IV, 25% III, 14% as level II and 8% as level I. There were similar numbers of children from northern (53%) and southern (47%) Ghana and the distribution of cerebral palsy did not differ by North/South. Households living in the north were more likely to be in the poorest quartile. Overall, of the 37 children of pre-school/school age, only 10 (26%) were currently enrolled in school and 11 (29%) had ever attended school. Caregivers were nearly all female (97%) and the vast majority were mothers (80%) or grandparents (15%) of the children with cerebral palsy for whom they were providing care. The majority of caregivers (61%) reported not having engaged in income generating activities in the past month and 43% had never attended school. While most caregivers were married (70%), just under half (49%) had fathers living in the same house as their affected child.

Child Feeding

In terms of psychometric properties, for each item missing data was low (<1%) and maximum endorsement frequencies were below 80% which is considered acceptable.[23] The summary score showed good internal consistency with a Cronbach's alpha of 0.8 and item-total correlations above 0.7.[23]

Difficulties with the child's feeding were commonly reported (figure 1). More than half the caregivers reported their child experienced feeding problems at least 'sometimes' in all eight domains. The majority of caregivers (75%) reported their child 'always' needed help with feeding. Two thirds of caregivers reported 'always' worrying about their child's feeding and 50% 'always' worrying their child was not eating enough. Similar findings were observed if children under 3 years, who may be expected because of their age to experience feeding difficulties, were excluded (data not presented). The median composite feeding score was 28.1 (SD 31.7) out of a highest possible score ('no difficulties') of 100.

Prevalence of Malnutrition

A high proportion of the children in this sample were categorised as malnourished (table 2): 65% of children aged <5 years were underweight, 54% as stunted and 58% as wasted. Including the older

children, 56% were stunted and 63% (<10 years only) were underweight. All mean z scores were below -1.8. We conducted a sensitivity analysis, excluding children with imputed height data and the results were broadly similar. According to the MUAC measurements, only 21% of the sample were classified as wasted.

Factors associated with malnutrition

As shown in table 3, the risk of being underweight was significantly higher among children experiencing the greatest difficulties with feeding (i.e. in the highest feeding score tertile: OR 10.7 95% CI 2.3-49.6, p=0.002. Prevalence of underweight was higher among children with severe (71%) rather than mild (43%) cerebral palsy, but this was of borderline significance (OR 3.6 95% CI 0.9-13.6, p=0.06). No significant association was found with the other variables assessed. These results remained similar with adjustment for all variables included in table 3.

Caregiver and family quality of life

In terms of psychometric properties of the PedsQL in this setting, the proportion of missing data was <1% and floor and ceiling effects were less than 80% for each summary score. Good total- and sub-scale internal consistency was demonstrated by high Cronbach's alpha values (>0.7) and item total correlations (range:0.49-0.81). The only exception was the 3-item communication sub-scale which had a Cronbach's alpha of 0.54.

Caregiver QoL scores in this study population were low: the median summary total score was 12.5 (Interquartile Range, IQR 20.8) out of a maximum score of 100 (highest QoL). Median summary scores for the sub-scales ranged from 0 (IQR 16.6) for daily activities to 16.7 (IQR 25.0) for physical functioning.

Quality of life scores were significantly lower among caregivers whose children had the greatest difficulties with feeding (median score 9.0) compared to those with least difficulties (24.6, p=0.004) even with adjustment for potential confounders (caregiver and child age, SES, north/south and cerebral palsy severity). QoL was similar for caregivers with a child with cerebral palsy who was underweight (10.8) compared to caregivers whose child was not underweight (11.8, p=0.12).

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Discussion

The prevalence of malnutrition in this population of children with cerebral palsy from rural Ghana was very high. Caregiver-reported difficulties with child's feeding were common and greater feeding difficulties were strongly associated with the child being underweight. Feeding difficulties, but not the presence of malnutrition, were also significantly associated with poorer caregiver QoL. This study contributes to the limited empirical data available on cerebral palsy, malnutrition and caregiver QoL in LMICs.

Approximately two-thirds of this study population were malnourished and over a third of was severe. The proportion of children underweight was almost six times the Ghana national average, according to the 2014 Demographic and Health Survey, which found 11% of children under 5 years were underweight and 2% severely underweight (ranging from 5.9-10.5% and 0.7-2.5% respectively in the four study regions.[24] Similarly 58% were wasted and 54% were stunted compared to the national average of 5% and 19% respectively (range across study regions: 1.3-5.2% and 10.4-17.2% respectively).[24]

These findings support previous studies highlighting that malnutrition is common among children with cerebral palsy. The prevalence in the current study was higher than previously reported in both high and low income settings.[2] A recent study in Uganda, for example, which used the same growth reference standards, found that 52% of children with cerebral palsy were malnourished, with underweight being the most common category at 42%.[25] The lower prevalence in the Uganda study may be partly attributed to the lower proportion of the study children with severe cerebral palsy (53% in Ghana, 33% in Uganda). Furthermore the children were all attending a paediatric cerebral palsy clinic and may be at lower risk of malnutrition.

The proportion of children with severe malnutrition based on low MUAC was considerably lower (20%) than that based on low WHZ (57%). This discrepancy has been previously noted for children with cerebral palsy.[25] MUAC, therefore, may not be sufficiently sensitive for this population. This is of concern, particularly considering MUAC is a preferred measure for admission to therapeutic and supplementary feeding programmes.[26] One possible reason for the discrepancy could be that children with cerebral palsy mobilise more with their arms and thus MUAC is built up more than in other children, although as more than half of children were in the severe GMFCS category and would likely have weak spastic muscles this is unlikely to fully account for this discrepancy.. However, given that: all the other anthropometric indicators of malnutrition are strikingly high in this population and

underlying disability is a major risk factor for death among malnourished patients, [27] it could be argued that automatic referral of all children with cerebral palsy for nutritional support is warranted. Our data thus support calls for closer links between nutrition and disability services: despite great potential for synergy and benefit there are currently too few referrals from disability services to feeding programmes (and vice versa).[28] Improved training on and inclusion of disability within nutrition programmes and health services more broadly needs to be prioritised. Further, early detection of cerebral palsy accompanied by early intervention and regular monitoring with regards to nutritional status is needed to reduce the risk of malnutrition in this population.

Feeding difficulties were common among this population and children with the greatest feeding difficulties were significantly more likely to be underweight. Although this was a cross sectional study, this finding supports other studies showing that difficulties with feeding are a key mechanism linking cerebral palsy and malnutrition.[2]

Malnutrition was common even among children with mild and moderate cerebral palsy and arguably higher than might be expected considering their level of physical functioning. This highlights a need for further research exploring factors influencing their nutritional status and for interventions to train and support caregivers in appropriate feeding practises. The lack of significant association between being underweight and severity of cerebral palsy in this study may reflect the relatively small study sample, the broad categories of severity used as well as the high prevalence of malnutrition, as defined using WHO growth standards.

Greater feeding difficulties were associated with poorer caregiver QOL. This aligns with previous research showing that feeding difficulties can be stressful for carers as well as evidence that interventions which address feeding have a positive impact on QoL.[29] Possible reasons for this link include the emotional strain of feeding itself, associated with the child's motor deficit, drooling, choking and the additional help required, [10] and concerns about the nutritional intake of the child. In addition, feeding can be very time-consuming both in terms of food preparation and actual mealtimes, particularly for children with greatest feeding difficulties. This, in turn, limits time available for other activities including income-generation which can have substantial economic consequences for families living in poverty, especially in this context where caregivers are most commonly women and in half of households fathers were not living at home. The additional time and money required in food preparation and feeding has been noted previously as particularly challenging in LMIC.[30]. The relationship with QoL may also be cyclical: evidence from other settings

suggests that caregiver anxiety and depression is associated with more non-responsive or forceful feeding styles which may, in turn, contribute to the child's feeding difficulties. Further research, using qualitative methods is needed to more fully understand the mechanisms linking feeding with quality of life. Interestingly, caregiver QoL was not associated with their child's nutritional status. This suggests that the experience of feeding is the key issue for caregivers rather than their child's weight status. It may also reflect a historical perception of children with cerebral palsy as being expected to be thin and small. The negative association between QoL and feeding difficulties highlights the need for caregiver support with mealtime challenges through community-based programmes and nutritional services.

Strengths and limitations

This is the first study to explore malnutrition, feeding difficulties and caregiver QoL for children with cerebral palsy in Ghana and contributes to the overall lack of empirical data on this topic from low income countries. We used a standardised questionnaire and common anthropometric assessment methods.

There were some limitations. We did not include a control population without cerebral palsy against which to compare findings. The sample size was relatively small and therefore some caution is warranted in interpreting the findings. We did not assess additional factors that may affect child nutritional status, such as dietary intake, which deserves attention in future studies. We did not use other classification systems, besides the GMFCS and our feeding difficulties scale, limiting the data available on the clinical features of our study population. Most children were identified through community programmes/case finding in rural areas and therefore findings may not be generalisable to wealthier urban areas. This approach may also have resulted in over-representation of more severe cases of cerebral palsy in our sample which should be taken into consideration in interpretation of our findings. However, our data suggested that malnutrition was also common among children with mild cerebral palsy and we adjusted for severity level in our multivariate analysis. Further, the inclusion of children identified in rural communities makes an important contribution to the literature as other similar studies in LMIC have typically recruited children only from hospitals which may miss children from the most under-served areas.[25, 31] This study found that feeding difficulties are common in this study population and are associated with under-nutrition and poor caregiver quality of life. However, it is not possible to determine the causal pathways between these variables, given the cross-sectional nature of this study and this deserves attention in future research.

Height measurement is challenging and particularly among children with cerebral palsy who can have contractures and involuntary muscle spasms. In the absence of global guidelines we used knee height as a proxy for missing height data. In a sensitivity analysis, excluding those with imputed height, the findings remained essentially unchanged suggesting that this was not a major problem. Postural difficulties may have resulted in us overestimating height/length. This would have resulted in falsely higher levels of wasting and falsely lower stunting (in contrast to our population, in most nutritionally at-risk children, stunting is normally most prevalent problem and wasting the least). Even if such measurement errors do explain part of our results, the general conclusion of high malnutrition still applies: weight-for-age would not be affected yet strongly suggests high levels of malnutrition. The finding, in this and previous studies[2, 25], that malnutrition is very common when defined using the WHO growth standards requires some reflection as to whether these are the most appropriate growth charts to use for children with cerebral palsy. Some previous studies have used cerebral palsy growth reference curves. However, these are out-dated, and in contrast to the WHO growth reference standards, they only describe how children do grow rather than how they should grow in ideal circumstances. Recent data have supported the use of WHO growth reference z-scores in assessing children with cerebral palsy.[32] Finally, we acknowledge the discrepancy between acute malnutrition as assessed by MUAC and by WHZ which has also been observed in other populations.[33] A key future area for research is to identify which measure is most predictive of future risk and which is most appropriate and scalable in routine programming.[34] Low MUAC is the strongest predictor of mortality in many other populations and has significant advantages of simplicity, speed and affordability and thus has the best potential for widespread use in resource-poor setting: but work is needed to explore whether the same advantages and same MUAC treatment thresholds apply to populations of disabled children.[35-37]

Conclusion

The prevalence of malnutrition among children with cerebral palsy in Ghana was very high. Feeding difficulties were common and associated with both increased risk of malnutrition and poorer caregiver QoL. There is an urgent need to better link nutrition and disability services. This should include appropriate, accessible caregiver training and support around feeding practises of their children with cerebral palsy, both to improve child nutritional status and the well-being of their caregivers. Further research on anthropometric assessment for children with cerebral palsy is also needed.

Acknowledgements

References

1.   Donald KA, Kakooza AM, Wammanda RD, Mallewa M, Samia P, Babakir H, et al. Pediatric Cerebral Palsy in Africa Where Are We? Journal of Child Neurology. 2014;30(8):963-71

2.   Aggarwal S, Chadha R, Pathak R. Nutritional status and growth in children with cerebral palsy: a review. International Journal of Medical Science and Public Health. 2015;4(6):737-44

3.   Stevenson RD, Hayes RP, Cater LV, Blackman JA. Clinical correlates of linear growth in children with cerebral palsy. Dev Med Child Neurol. 1994;36(2):135-42

4.   Gisel EG, Tessier MJ, Lapierre G, Seidman E, Drouin E, Filion G. Feeding Management of Children with Severe Cerebral Palsy and Eating Impairment. Physical & Occupational Therapy in Pediatrics. 2003;23(2):19-44

5.   Sullivan P, Lambert B, Rose M, Ford-Adams M, Johnson A, Griffiths P. Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study. Developmental Medicine & Child Neurology. 2000;42(10):674-80

6.   Black MM. Commentary: Feeding problems: An ecological perspective. Journal of pediatric psychology. 1999;24(3):217-9

7.   Dan B. Nutrition, brain function, and plasticity in cerebral palsy. Dev Med Child Neurol. 2016 Sep;58(9):890

8.   Kerac M, Postels DG, Mallewa M, Jalloh AA, Voskuijl WP, Groce N, et al. The interaction of malnutrition and neurologic disability in Africa. Seminars in pediatric neurology. 2014;21(1):42-9

9.   Groce NE, Kerac M, Farkas A, Schultink W, Bieler RB. Inclusive nutrition for children and adults with disabilities. The Lancet Global Health. 2013;1(4):180-1

10.   Adams M, Khan N, Begum S, Wirz S, Hesketh T, Pring T. Feeding difficulties in children with cerebral palsy: low cost caregiver training in Dhaka, Bangladesh. Child: care, health and development. 2011;38(6):878-88

11.   Mobarak R, Khan NZ, Munir S, Zaman SS, McConachie H. Predictors of stress in mothers of children with cerebral palsy in Bangladesh. J Pediatr Psychol. 2000 Sep;25(6):427-33

12.   Sullivan PB, Juszczak E, Lambert BR, Rose M, Ford-Adams ME, Johnson A. Impact of feeding problems on nutritional intake and growth: Oxford Feeding Study II. Dev Med Child Neurol. 2002 Jul;44(7):461-7

13.   Evaluating the impact of a community –based parent training programme for children with Cerebral Palsy in Ghana. International Centre for Evidence in Disability Study Report. Available at: http://disabilitycentre.lshtm.ac.uk/files/2014/07/Ghanacountry-reportfinal.pdf. Accessed 16th february 2018 2016.

14.   Wood E, Rosenbaum P. The gross motor function classification system for cerebral palsy: a study of reliability and stability over time. Developmental Medicine & Child Neurology. 2000;42(05):292-6

15.   Varni JW, Sherman SA, Burwinkle TM, Dickinson PE, Dixon P. The PedsQL™ family impact module: preliminary reliability and validity. Health and quality of life outcomes. 2004;2(1):55

16.   Varni JW, Burwinkle TM, Seid M, Skarr D. The PedsQL™* 4.0 as a Pediatric Population Health Measure: Feasibility, Reliability, and Validity. Ambulatory Pediatrics. 2003;3(6):329-41

17.   Froehlich-Grobe K, Nary DE, Van Sciver A, Lee J, Little TD. Measuring height without a stadiometer: empirical investigation of four height estimates among wheelchair users. American journal of physical medicine & rehabilitation/Association of Academic Physiatrists. 2011;90(8):658

18.   WHO child growth standards : length/height-for-age, weight-for-age, weight-for-length, weight-forheight and body mass index-for-age : methods and development. (Technical Report) [cited 15.3.2010]. Available from: http://www.who.int/childgrowth/publications/technical_report_pub/en/index.html.

19.   Emergency Nutrition Assessment (ENA). Software for standardized monitoring and assessment of relief and transitions (SMART). Available: http://www.nutrisurvey.de/ena/ena.html Accessed 29th May 2016.

20.   Organization WH, Unicef. WHO child growth standards and the identification of severe acute malnutrition in infants and children: a joint statement by the World Health Organization and the United Nations Children's Fund. Geneva: World Health Organization. 2009

21.   Crowe S, Seal A, Grijalva-Eternod C, Kerac M. Effect of nutrition survey 'cleaning criteria' on estimates of malnutrition prevalence and disease burden: secondary data analysis. PeerJ. 2014;2:e380

22.   Brooks J, Day S, Shavelle R, Strauss D. Low weight, morbidity, and mortality in children with cerebral palsy: new clinical growth charts. Pediatrics. 2011 Aug;128(2):e299-307

23.   Lamping DL, Schroter S, Marquis P, Marrel A, Duprat-Lomon I, Sagnier PP. The community-acquired pneumonia symptom questionnaire: a new, patient-based outcome measure to evaluate symptoms in patients with community-acquired pneumonia. Chest. 2002 Sep;122(3):920-9

24.   Ghana Demographic and Health Survey 2014. Rockville, Maryland, USA: Ghana Statistical Service, Ghana Health Service, ICF International, 2015.

25.   Kakooza-Mwesige A, Tumwine JK, Eliasson AC, Namusoke HK, Forssberg H. Malnutrition is common in Ugandan children with cerebral palsy, particularly those over the age of five and those who had neonatal complications. Acta Paediatrica. 2015;104(12):1259-68

26.   Briend A, Alvarez J-L, Avril N, Bahwere P, Bailey J, Berkley JA, et al. Low mid-upper arm circumference identifies children with a high risk of death who should be the priority target for treatment. BMC Nutrition. 2016;2(1):63

27.   Kerac M, Bunn J, Chagaluka G, Bahwere P, Tomkins A, Collins S, et al. Follow-Up of Post-Discharge Growth and Mortality after Treatment for Severe Acute Malnutrition (FuSAM Study): A Prospective Cohort Study. PLoS One. 2014;9(6):e96030

28.   Groce N, Challenger E, Berman-Bieler R, Farkas A, Yilmaz N, Schultink W, et al. Malnutrition and disability: unexplored opportunities for collaboration. Paediatr Int Child Health. 2014 Nov;34(4):308-14

29.   Sullivan PB, Juszczak E, Bachlet AM, Thomas AG, Lambert B, Vernon-Roberts A, et al. Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. Dev Med Child Neurol. 2004 Dec;46(12):796-800

30.   Yousafzai AK, Pagedar S, Wirz S, Filteau S. Beliefs about feeding practices and nutrition for children with disabilities among families in Dharavi, Mumbai. International Journal of Rehabilitation Research. 2003;26(1):33

31.   Johnson A, Gambrah-Sampaney C, Khurana E, Baier J, Baranov E, Monokwane B, et al. Risk Factors for Malnutrition Among Children With Cerebral Palsy in Botswana. Pediatr Neurol. 2017 May;70:50-5

32.   Karagiozoglou-Lampoudi T, Daskalou E, Vargiami E, Zafeiriou D. Identification of feeding risk factors for impaired nutrition status in paediatric patients with cerebral palsy. Acta paediatrica. 2012;101(6):649-54

33.   Grellety E, Golden MH. Weight-for-height and mid-upper-arm circumference should be used independently to diagnose acute malnutrition: policy implications. BMC Nutrition. 2016;2(1):1-17

34.   Myatt M, Khara T, Collins S. A review of methods to detect cases of severely malnourished children in the community for their admission into community-based therapeutic care programs. Food Nutr Bull. 2006 Sep;27(3 Suppl):S7-23

35.   ENN, SCUK, ACF, UNHCR. Mid Upper Arm Circumference and Weight-for-Height Z-score as indicators of severe acute malnutrition: a consultation of operational agencies and academic specialists to understand the evidence, identify knowledge gaps and to inform operational guidance. Final review paper 2012. Available at http://www.cmamforum.org/Pool/Resources/MUAC-WFH-Report-ENN-2013.pdf. Accessed 3 Feb 2016.

36.   A B, Marie B, Fontaine O, Garenna M. Mid-upper arm circumference and weight-for-height to identify high-risk malnourished under-five children. Matern Child Nutr. 2012;8(1):130-3

37.   Bhutta Z, Berkley J, R. B, Kerac M, Trehan I, Briend A. Severe childhood malnutrition. Nat Rev Dis Primers. 2017;21(3):170-67

Figure 1 – Caregiver reported difficulties with child's feeding (caregivers were asked how often these aspects of feeding were a problem).

Table 1: Socio-demographic characteristics of the children with cerebral palsy and their caregivers

	N	%
Child Variables		
Sex		
Male	41	54%
Female	35	46%
Age Group		
18months-2 years	31	41%
3-4 years	23	31%
5+ years	21	28%
Region		
North	40	53%
South	36	47%
Cerebral Palsy Severity		
I (mild)	6	8%
II (mild)	11	14%
III (moderate	19	25%
IV (Severe)	21	28%
V (severe)	19	25%
Caregiver/household variables		
Age group		
<30	23	30%
30-40	34	45%
40-60	15	20%
60+	4	5%
Relationship to child		
Mother	61	80%
Father	1	1%
Grandparent	11	15%
Other	3	3%
Worked in last month		
No	46	61%
Yes	30	39%
Marital status		
Married/living together	53	70%
Divorced/separated	6	8%
Widowed	6	8%
Single	11	15%
Ever attended school		
No	33	43%
Yes	43	56%
Highest level completed		
None	33	43%
Primary	18	24%
Junior High	13	17%
Senior High	9	12%
Tertiary	3	4%

Table 2 Prevalence of malnutrition and mean z scores

	All ages[a]		Children <5 years	
	N	% (95% CI)	N	% (95% CI)
Weight for Age				
'Normal' (WAZ ≥2)	24	37% *(25.8-49.5)	17	35% (22.8-50.3)
Underweight (≥ -3 to <2)	15	23% (14.2-35.1)	13	27% (16.1-41.8)
Severely underweight (<-3)	26	40% (28.5-52.6)	18	38% (24.6-52.4)
Mean WAZ (95% CI)	-2.6 (-3.0- -2.2)		-2.5 (-3.0- -2.1)	
Height for Age				
'Normal' (HAZ ≥2)	29	41% (29.8-52.9)	24	46% (32.8-60.1)
Stunted (≥ -3 to <2)	18	25% (16.4-37.0)	14	27% (16.4-40.9)
Severely stunted (<-3)	24	34% (23.6-45.8)	14	27% (16.4-40.9)
Mean HAZ (95% CI)	-2.3 (-2.6- -1.9)		-2.1 (-2.5- -1.7)	
Weight for height				
'Normal' (WHZ ≥2)			20	42% (28.3-56.4)
Wasted (≥ -3 to <2)			16	33% (21.1-48.2)
Severely wasted (<-3)			12	25% (14.5-39.6)
Mean WHZ (95% CI)			-1.9 (-2.3 - -1.5)	
Middle Upper Arm Circumference				
'Normal' (>=125mm)			43	80% (66.4-88.9)
Wasted (115-124mm)			10	19% (10.1-31.2)
Severely wasted (<115mm)			1	1 % (0-13)
Mean MUAC (95% CI)			143.0 (127.2-128.8)	

[a]Weight for age calculated for children <10 years as per guidelines. WAZ= Weight for Age Z score; HAZ=Height for Age Z score; WHZ=Weight for Height Z score; MUAC=Middle Upper Arm Circumference

Table 3: Association between underweight[b] and socio-demographic, clinical and feeding variables among children aged under 10 years

	N	Number underweight[b] (%)	Age and Sex adjusted odds Ratios (95% CI)
Child variables			
Age			
18months-2yrs	28	21 (75%)	1.6 (0.4-5.8)
3-4 years	20	10 (50%)	0.6 (0.2-2.3)
5+ years	16	10 (63%)	Reference
Sex			
Male	36	23 (65%)	Reference
Female	28	18 (65%)	1.1 (0.4-3.1)
CP severity			
Mild	14	6 (43%)	Reference
Moderate	15	10 (67%)	2.0 (0.4-8.9)
Severe	35	25 (71%)	3.6 (0.9-13.6)
Serious health problem in past 12 months			
No	11	65%	Reference
Yes	33	65%	0.9 (0.3-3.1)
Feeding difficulties			
Least difficulties	17	6 (35%)	Reference
Middle	22	13 (59%)	3.0 (0.7-11.8)
Greatest difficulties	25	22 (89%)	10.7 (2.3-49.6) [a]
Caregiver/Household variables			
Age			
<30 years	20	13 (65%)	1.1 (0.3-5.0)
30-40 years	30	20 (67%)	1.6 (0.4-6.3)
>40 years	14	8 (57%)	Reference
Education			
None	27	19 (70%)	Reference
Some	37	22 (59%)	0.8 (0.3-2.3)
Socio-economic status			
Least poor	21	12 (57%)	Reference
Medium	19	11 (53%)	1.0 (0.3-3.6)
Poorest	23	18 (78%)	2.7 (0.7-10.6)
North/South Ghana			
South	34	19 (56%)	Reference
North	31	22 (71%)	1.7 (0.6-5.1)

[a] Remained independently associated with being underweight with adjustment for all other variables (as potential confounders) included in the table. [b] Underweight is defined as any weight-for age z-score <-2)

Table 4: Association between caregiver quality of life with feeding difficulties and malnutrition

	N	Median (SD) total QoL score	Adjusted[a] coefficient	Adjusted [a] P-value
Child variables				
Feeding difficulties				
Least difficulties	24	24.6 (32.6))	Reference[b]	Reference[b]
Middle	24	11.5 (20.8)	-1.06	0.06
Greatest difficulties	29	9.0 (1.04)	-1.86	0.004
Underweight				
Not underweight	24	10.8 (22.2)	Reference[c]	Reference[c]
Underweight	41	11.8 (18.8)	0.77	0.12

NB: For these analyses, QoL life data were transformed (square root) because the data were skewed.
[a]P-value from linear regression analysis adjusted for caregiver and child age, SES, north/south, severity of cerebral palsy [b] also adjusted for underweight [c]also adjusted for feeding difficulties