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RESEARCH ARTICLE

# Current practices and challenges of registered dietitians in the nutritional management of children with cerebral palsy in South Africa

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**Background:** Feeding difficulties and subsequent malnutrition are common in children with cerebral palsy (CP).
**Objectives:** A study was undertaken to determine the current practices and challenges of South African registered dietitians (SA RD) regarding the nutritional management of children with CP, to compare these practices with international guidelines and to compare the practices of private- and public-sector dietitians.
**Design:** This was a cross-sectional descriptive study with an analytical component.
**Subjects and outcome measures:** The SA RDs completed an online questionnaire, which was developed according to the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) guidelines. Participant answers were scored to assess their management of children with CP.
**Results:** Of the 87 SA RDs who participated, 78 had work experience in CP (40 public and 38 private sector). Over two-thirds ($n = 62/87$, 71.2%) received training on the management of CP at university, albeit inadequate ($n = 42/62$, 67.7%). Common challenges that affect RDs' management are poor caregiver compliance ($n = 72$; 92.2%) and poor networking between healthcare professionals (HCPs) ($n = 60$; 77.0%). The SA RD ($n = 78$) management of children with CP was significantly different from the ESPGHAN guidelines ($p < 0.001$). When comparing the total practice score, no significant difference was found between private- and public-sector RDs. The SA RDs did not achieve many of the recommended practices, particularly those pertaining to anthropometry.
**Conclusions:** Improved training of SA RDs in the assessment and management of children with CP, and addressing barriers such as poor caregiver compliance, would enhance SA RDs' competence to improve the nutritional management of children with CP.

**Keywords** cerebral palsy, nutritional management, South African registered dietitians

## Introduction

Cerebral palsy (CP) is the most common physical disability in childhood.[1] CP is caused by an injury to the brain or due to abnormal development of the maturing brain.[2] There is limited information available on South African (SA) statistics, yet the latest data describe the prevalence of children with CP in SA (0.3–1%) as higher than the global statistic (0.21%).[3,4]

Children with CP are at risk of malnutrition, faltering growth and nutritional comorbidities due to many factors including feeding difficulties and gastrointestinal (GI) symptoms.[5] Adequate nutritional management is vital to prevent the onset of malnutrition and its consequences for poor development and health.[6] Children who are well nourished and able to feed adequately have a better quality of life both functionally and physically.[6]

Caregiver challenges in feeding their children with CP have been examined in the literature. Common challenges are feeding problems, which include vomiting, choking, prolonged mealtimes and constipation.[7] Concerns over these feeding difficulties can significantly decrease the quality of life of both caregiver and child.[8]

There is a paucity of data on how children with CP are managed nutritionally in SA, as well as the barriers faced by registered dietitians (RDs) to provide their best care. SA studies found that feeding problems in children with CP were not adequately addressed because less than half of children in need of nutritional advice were referred to RDs.[9,10] Similar studies[11,12] from the UK and Saudi Arabia have described how RDs who were part of a multidisciplinary team were more likely to use best dietetic practices[12] and receive more referrals.[11] Very few RDs[11,12] included a variety of anthropometric measurements, including skinfold thickness, to assess nutritional status, which is important for children with CP.[13] Lack of training[11,12] and time[11] have contributed to this gap in practice. As there are no specific SA guidelines on how to manage these children nutritionally, the international guidelines compiled by the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN)[13] (Table 1) are a valuable resource for SA RDs.

The aims of this study were: (i) to describe the current practice of SA RDs regarding the nutritional management of children with CP in SA; (ii) to compare these practices with international guidelines; (iii) to compare the practices of private and public sector SA RDs; and, finally, (iv) to identify the challenges and barriers faced by SA RDs in providing optimal nutritional care to children with CP. The findings and recommendations from this study will provide insight into the practices of SA RDs and how these compare with international guidelines, with the aim of improving the nutritional status of these vulnerable children.

## Methods

### *Study population and design*

A cross-sectional descriptive study, which included an analytical component, was conducted. The study population was defined as all SA RDs who are involved in the nutritional care of children

**Table 1:** Summary of personal information of South African registered dietitians with an interest in paediatrics ($N = 87$).

| Variable | $N = 87$ *n* (%) |
|---|---|
| Gender: | |
| Female | 84 (96.6) |
| Male | 3 (3.4) |
| Number of SA RDs per sector: | |
| Public sector | 40 (51.0) |
| Private sector | 38 (49.0) |
| Number of SA RDs who received CP training: | |
| Yes | 62 (71.3) |
| No | 25 (28.7) |
| Number of SA RDs who were satisfied with training received: | |
| Yes | 20 (32.3) |
| No | 42 (67.7) |

in SA. Such data were obtained from the Health Professions Council of South Africa (HPCSA), the Association of Dietetics in South Africa (ADSA), Medpages (an African database of healthcare contact information) and 72 provincial SA hospitals. The population of RDs who manage CP patients was estimated as $N = 209$, consisting of 112 RDs in the private sector and 97 RDs in the public sector. All members of the study population were invited to participate.

To test the null hypothesis that the practices of private- and public-sector RDs are equal, the required sample size for each group was calculated at 64. However, due to no further responses after reminder advertisements of the study were sent, once a sample size of 40 public and 38 private sector RDs was reached, interim analysis revealed that the minimum difference of clinical importance (10%) had not been achieved and further sample collection was discontinued.

## Methods

An online survey was electronically sent between March and May 2019 to all members of the Association for Dietetics in South Africa (ADSA) via an ADSA newsletter. Additionally, RDs were contacted electronically after compiling a database of paediatric RDs utilising Medpages and lists of CP clinics. Reminder emails were sent out again after the first invitation to increase the response rate.

### Research instrument

The research instrument was a questionnaire incorporated into an online survey using the web-based program SurveyMonkey. This questionnaire was developed based on the latest published guidelines on the nutritional care of children with CP by ESPGHAN[13] and included those guidelines pertaining to dietetic management. It comprised two sections. The first section included six demographic questions, which were answered by all RDs. The second section continued for RDs who regularly managed children with CP, comprising 26 questions (5 dichotomous, 13 multiple choice and 8 open-ended questions) on aspects of nutritional care for children with CP. The questions in the second section were designed to assess whether the RD's management of children with CP followed the recommended practices described in the ESPGHAN[13] guidelines. The questionnaire was used to assess the RD's adherence to 28 such guidelines. For each guideline that the RD followed, they scored one point out of a possible 28 points. A total practice score was calculated out of 28 and expressed as a percentage. The total practice percentages of all SA RDs were compared with the ESPGHAN guidelines. Additionally, the total practice percentages of the public-sector RDs were compared with the private-sector RDs.

Content validity was established by the review of two experts in paediatric nutrition and on the grounds that the questionnaire was developed from guidelines compiled by ESPGHAN,[13] which is an authoritative body as all information is derived from scientific evidence. A pilot study was used to determine face validity. Final-year dietetic students were chosen for this purpose as they had theoretical knowledge of the nutritional management of children with CP and thus could provide meaningful input concerning the clarity of questions. They evaluated the procedure of answering and submitting the electronic survey. Five students volunteered and provided feedback, which helped to clarify the instructions to complete the survey and resulted in the aim of the study being explained more clearly. Registered dietitians were not chosen to be part of the pilot study because the pool of paediatric RDs is small and if they took part in the pilot study they would not be eligible to participate in the study.

### Data analysis

Data from the survey were imported from SurveyMonkey in a Microsoft Excel (Microsoft Corp, Redmond, WA, USA) spreadsheet and analysed using the statistical package IBM SPSS®, version 25 (IBM Corp, Armonk, NY, USA). Quantitative data were prepared for statistical analysis by means of coding. Responses to open-ended questions were categorised into familiar themes. The RDs' responses were scored on 28 guidelines (referred to as a total practice score) from the ESPGHAN[13] recommendations and a percentage was calculated, which indicated the degree to which these guidelines were achieved (Table 3).

Two null hypotheses were tested. The first hypothesis was that there was no difference between the mean total practice scores of the population of SA RDs in the study and the expected score of 100% practice of the ESPGHAN[13] guidelines. The mean total practice score of all the RDs were compared with a score of 100% representing the guidelines using the one-sample Wilcoxon signed rank test. The second hypothesis was that there was no difference in mean total practice scores between the private and public RDs. The mean total practice score of public and private practicing RDs were compared using the two-sided, two-sample equal-variance Mann–Whitney U test. Individual items were compared between independent groups using Pearson's chi-square or Fisher's exact tests. A $p$-value $< 0.05$ indicated a significant difference between the two groups in all tests.

### Ethics

This study was granted ethics approval by the Health Research Ethics Committee of the Faculty of Medicine and Health Sciences, Stellenbosch University (HREC Ref: S18/08/170) and was conducted according to the ethical guidelines of the Declaration of Helsinki. Participants provided informed consent by agreeing voluntarily to participate in the study before gaining access to the survey. The survey was anonymous and confidential because responses cannot be linked to any participant.

## Results

Ninety-three RDs consented to participate; however, 87 completed the questionnaire and were included in the study. The mean age of the RDs was 33.8 years (SD ± 6.9), the median years of dietetic experience was 10 years (range = 1–28) and 7 of the 9 SA provinces were represented. Over two-thirds ($n$ = 62/87, 71.3%) had received training on the management of CP at university but the majority ($n$ = 42/62, 67.7%) felt the training was inadequate (Tables 1 and 2).

Seventy-eight (78/87, 90.0%) RDs had work experience in CP management (40 public-sector and 38 private-sector RDs) (Table 1). The ESPGHAN[13] guidelines used in the questionnaire are presented in Table 3. The guidelines performed by most RDs were in identifying undernutrition (guidelines 6 and 7) ($n$ = 73, 93.6%) and correctly including early feeding history as part of assessment (guideline 9) ($n$ = 74, 94.9%), while the least performed guideline was the anthropometric guidelines for measuring fat mass (guidelines 4 and 5) ($n$ = 4, 5.1%). Although 39.7% ($n$ = 31) used standard growth curves (Centers for Disease Control and Prevention [CDC] as well as World Health Organisation child growth standards [WHO]) (guideline 10), many RDs used a combination of growth curves for assessment. Public-sector RDs performed significantly more of the guidelines than private-sector RDs by being part of a multidisciplinary team involving more than one other healthcare profession (guideline 1) ($p$ = 0.009). Private-sector RDs performed significantly better than public-sector RDs on the guidelines, which recommend regular micronutrient assessment (guideline 11) ($p$ = 0.002), estimating energy (guideline 12) ($p$ = 0.011) and micronutrient requirements (guideline 14) ($p$ = 0.043), prescribing supplementary protein in specific circumstances (guideline 15) ($p$ = 0.003) and the trial use of whey-based formula in gastro-oesophageal reflux (GOR) (guideline 21) ($p$ = 0.001) (Table 3).

The nutritional assessments during follow-up visits were carried out by a lower percentage of RDs compared with nutritional assessments done during the first assessment. The measurement of triceps skinfold thickness (TST) for the determination of body fat (which is a requirement of the ESPGHAN[13] guidelines) was the least used method, changing from 9.0% for the first evaluation to 1.3% at the 12-month evaluation. Those RDs who investigated micronutrient status mostly considered iron, vitamin D and calcium while 23.1% did not consider any micronutrients. Clinical signs of malnutrition were not specifically defined but at least 50% of the RDs consistently monitored clinical signs (Table 4).

**Table 2:** Provinces where South African registered dietitians reside and universities attended ($N$ = 87)

| Province/university | *n* (%) |
|---|---|
| Province: | |
| Eastern Cape | 8 (9.2) |
| Gauteng | 33 (37.9) |
| KwaZulu-Natal | 15 (17.3) |
| Limpopo | 2 (2.3) |
| North-West | 3 (3.4) |
| Northern Cape | 2 (2.3) |
| Western Cape | 24 (27.6) |
| University: | |
| Pretoria University | 19 (21.8) |
| Stellenbosch University | 18 (20.7) |
| University of Cape Town | 6 (6.9) |
| University of KwaZulu-Natal | 13 (14.9) |
| University of Limpopo | 5 (5.7) |
| University of North-West | 16 (18.4) |
| University of the Free State | 4 (4.6) |
| University of Western Cape | 6 (6.9) |

A significant difference was found between the total practice score of the SA RDs and the ESPGHAN[13] guidelines. The median total practice score of the total group ($n$ = 78) was 60.7% (IQR 53.6%, 67.9%) (one-sample Wilcoxon signed rank test = −7.683, $p$ < 0.001). Conversely, the median total practice score of the public-sector dietitians ($n$ = 40) and private-sector dietitians ($n$ = 38) showed no difference (57.1% [IQR 51.8%, 67.9%] and 60.7% [IQR 57.1%, 71.4%] respectively) (independent-samples Mann–Whitney U test, $p$ = 0.090).

The SA RDs were posed open-ended questions to describe their challenges when managing children with CP (Figure 1) as well as their observations of the challenges that caregivers face when caring for their children with CP (Figure 2). The most common challenges faced by SA RDs include poor caregiver compliance (92.2%), poor networking between SA RDs and other HCPs (77.0%), difficulty in measuring anthropometry (65.4%) and inconsistent follow-up (61.5%) (Figure 1).

Additionally, SA RDs perceived that caregivers faced many challenges when supporting their children with CP. Lack of financial resources (80.8%) was perceived as the most common obstacle, followed by meals taking too long to consume (68.0%), lack of suitable equipment to prepare the food (62.8%) and a lack of nutritional knowledge (59.0%). Feeding difficulties (gagging and vomiting [55.1%], fussy eating [55.1%] and choking [51.3%]) during meals were also perceived as challenges (Figure 2).

## Discussion and recommendations

This research aimed to determine the practices and challenges of SA RDs regarding the nutritional management of children with CP. These practices were compared with international guidelines,[13] and the practices of private- and public-sector SA RDs were also compared. The study found that SA RDs successfully achieved certain practices such as managing patients as part of a multidisciplinary team and initiating enteral feeding appropriately but fell short of the ESPGHAN[13] guidelines, particularly in anthropometric assessment. In total, the practices of publicly and privately practicing SA RDs were similar. Additionally, SA RDs are faced with many obstacles that impede their ability to succeed.

### *Nutritional assessment*

The anthropometric assessment of children with CP is challenging because weight and height measurements can be unreliable due to their physical attributes. Additionally, these children may be shorter and have reduced lean body mass and higher fat mass compared with typically developed children,[13,14,15] possibly resulting in an incorrect interpretation of a body mass index (BMI) or $z$-score.[15] For this reason, fat mass and fat-free mass using TST is a more reliable indicator of malnutrition in this population group.[16] Very few (5%) SA RDs complied with this practice, and previous studies attributed it to lack of time and appropriate training.[11,12] The use of alternative segmental length measures (e.g. knee height or

**Table 3:** Achievement of the selected ESPGHAN## guidelines by South African registered dietitians, public-sector and private-sector dietitians and *p*-values of the tests# comparing the two sectors

| Guideline | Total dietitians (*N* = 78) *n* (%) | Public sector (*N* = 40) *n* (%) | Private sector (*N* = 38) *n* (%) | *p*-value# |
|---|---|---|---|---|
| 1. Nutritional management is provided while consulting as part of a multidisciplinary team | 66 (84.6) | 38 (95.0) | 28 (73.7) | 0.009* |
| 2. Using additional types of anthropometry than weight and height when assessing patients | 52 (66.7) | 30 (75.0) | 22 (57.9) | 0.109 |
| 3. Knee height or tibial length is used routinely when linear height is not easily measured | 25 (32.1) | 11 (27.5) | 14 (36.8) | 0.377 |
| 4. Fat mass by triceps skinfold thickness (TST) is routinely measured to assess patients | 4 (5.1) | 2 (5.0) | 2 (5.3) | 1.000 |
| 5. The use of follow-up anthropometry (weight, length, fat mass) at least six monthly | 4 (5.1) | 2 (5.0) | 2 (5.3) | 1.000 |
| 6. Undernutrition is identified based on anthropometry | 73 (93.6) | 36 (90.0) | 37 (97.4) | 0.184 |
| 7. The use of one or more red flags to identify undernutrition:<br>• physical signs of undernutrition<br>• weight-for-age z score < 2<br>• TST < 10th centile for age and sex<br>• Mid-upper arm fat or muscle area < 10th centile<br>• Faltering weight | 73 (93.6) | 36 (90.0) | 37 (97.4) | 0.359 |
| 8. Regular monitoring of bodyweight and fat mass to estimate energy requirements | 18 (23.1) | 7 (17.5) | 11 (28.9) | 0.230 |
| 9. Include feeding history starting from early infancy to assess patients | 74 (94.9) | 38 (95.0) | 36 (94.7) | 0.958 |
| 10. Cerebral palsy-specific growth charts are not used to identify undernutrition | 31 (39.7) | 16 (40.0) | 15 (39.5) | 0.962 |
| 11. Micronutrient status is determined annually | 17 (21.80) | 3 (7.5) | 14 (36.8) | 0.002* |
| 12. The use of dietary reference standards in typically developing children to estimate energy requirements | 44 (56.4) | 17 (42.5) | 27 (71.1) | 0.011* |
| 13. Using dietary reference intake (DRI) in typically developing children to estimate protein requirements | 46 (59.0) | 25 (62.5) | 21 (55.3) | 0.422 |
| 14. Using DRI in typically developing children to estimate micronutrient requirements | 36 (46.2) | 14 (35.0) | 22 (57.9) | 0.043* |
| 15. Prescribe supplementary protein in specific clinical situations like pressure ulcers or with low calorie requirement | 30 (38.5) | 9 (22.5) | 21 (55.3) | 0.003* |
| 16. Paying attention to hydration status | 63 (80.8) | 31 (77.5) | 32 (84.2) | 0.452 |
| 17. Paying attention to non-nutritional problems as these may contribute to feeding difficulties | 59 (75.6) | 30 (75.0) | 29 (76.3) | 0.892 |
| 18. Referral to speech therapist when there is oropharyngeal dysfunction | 69 (88.5) | 35 (87.5) | 34 (89.5) | 0.785 |
| 19. Consider the presence of oropharyngeal dysfunction in all patients with cerebral palsy even in absence of clinical signs | 42 (53.8) | 22 (55.0) | 20 (52.6) | 0.834 |
| 20. Modifying enteral nutrition and other therapeutic options when gastro-oesophageal reflux is present | 32 (41.0) | 16 (40.0) | 16 (42.1) | 0.850 |
| 21. Trial use of whey-based formula in gastro-oesophageal reflux | 9 (11.5) | 0 (0.0) | 9 (23.7) | 0.001* |
| 22. Increase fluid and fibre intake when constipated | 65 (83.3) | 33 (82.5) | 32 (84.2) | 0.839 |
| 23. Use of enteral feeding if it is nutritionally sufficient, safe, stress free and not prolonged | 66 (84.6) | 33 (82.5) | 33 (86.8) | 0.595 |
| 24. Recommend breast milk, standard infant formula or nutrient-dense formula in infants | 67 (85.9) | 34 (85.0) | 33 (86.8) | 0.815 |
| 25. Prescribe standard polymeric feeds with fibre in children > one year old | 50 (64.1) | 24 (60.0) | 26 (68.4) | 0.438 |
| 26. Use high-energy dense feeds with fibre, micronutrient replete formula for volume-restricted children | 55 (70.5) | 28 (70.0) | 27 (71.1) | 0.919 |
| 27. Prescribe low-fat, low-calorie, high-fibre, micronutrient replete formula for immobile children | 14 (17.9) | 6 (15.0) | 8 (21.1) | 0.486 |
| 28. Always involve parents and or caregivers in decision-making especially around gastrostomy feeding | 66 (84.6) | 33 (82.5) | 33 (86.8) | 0.595 |

#Pearson's chi-square test or Fisher's exact test.
##ESPGHAN: European Society for Paediatric Gastroenterology, Hepatology and Nutrition.
*Significant difference ($p < 0.05$).

tibial length) when linear height is not possible was not well practised by SA RDs, possibly due to absence of the specialised equipment required for accurate measurement. Additionally, the follow-up of children with CP, which should be six monthly, was not well achieved in this study, possibly due to the logistical problems highlighted by RDs as three out of five SA RDs reported that follow-up appointments were inconsistent.

Standard growth charts like the WHO growth curves are recommended by ESPGHAN[13] to monitor growth in children with CP because CP-specific growth charts, which were developed to account for the altered growth pattern often found in these children, show how children with CP are growing but not necessarily how they should grow.[13] In this study, just over a third of SA RDs complied with this practice. Additionally, SA RDs use a combination of growth charts to assess their

**Table 4:** Percentage of registered dietitians ($n = 78$) who perform nutritional assessments of children with cerebral palsy at various intervals

| Method of nutritional assessment according to ESPGHAN[#] guidelines | Frequency of evaluations | | | | |
|---|---|---|---|---|---|
| | First evaluation *n* (%) | After 1 month *n* (%) | After 3 months *n* (%) | After 6 months n (%) | After 12 months *n* (%) |
| Weight | 71 (91.0) | 51 (65.3) | 47 (60.2) | 44 (56.4) | 44 (56.4) |
| Height | 66 (84.6) | 24 (30.8) | 38 (48.7) | 37 (47.4) | 34 (43.6) |
| Knee height if linear length not accessible | 38 (48.7) | 11 (14.1) | 16 (20.5) | 19 (24.3) | 17 (21.8) |
| Body mass index | 54 (69.2) | 28 (36.0) | 31 (39.7) | 27 (34.6) | 26 (33.3) |
| Mid-upper arm circumference | 56 (71.8) | 27 (34.6) | 30 (38.5) | 31 (39.7) | 27 (34.6) |
| Triceps skinfold thickness | 7 (9.0) | 2 (2.6) | 3 (3.8) | 2 (2.6) | 1 (1.3) |
| Micronutrient blood status | 29 (37.2) | 4 (5.1) | 13 (16.7) | 8 (10.3) | 15 (19.2) |
| Clinical signs of malnutrition | 67 (86.0) | 45 (57.7) | 42 (53.8) | 39 (50.0) | 40 (51.3) |
| Feeding history | 72 (92.3) | 22 (28.2) | 20 (25.6) | 19 (24.3) | 17 (21.8) |
| Do not determine anthropometry | 0 (0.0) | 1 (1.3) | 2 (2.6) | 1 (1.3) | 1 (1.3) |

[#]ESPGHAN: European Society for Paediatric Gastroenterology, Hepatology and Nutrition guidelines.

patients, possibly due to the wide spectrum of CP patients they manage and the conflicting approaches in the literature. For instance, a Mexican study[17] found that CP-specific charts were a better reference for children with CP than the standard CDC charts.

Macro- and micronutrient requirements in children with CP are recommended in the ESPGHAN[13] guidelines to be the same as for neurotypical children, and individualised regular monitoring of bodyweight and fat composition to fine tune energy requirements is emphasised. The lack of follow-up appointments, which has been highlighted as a challenge by SA RDs, and their failure to take body fat measurements prevent this recommendation from being followed. The SA RDs use a variety of methods to calculate energy requirements, probably due to the vast spectrum of severity of this condition.[6] Six out of 10 SA RDs prescribed protein according to DRIs, while less than half increased protein requirements in accordance with the ESPGHAN[13] guidelines, which recommend an increase in the presence of pressure ulcers and when the energy requirement is reduced. The importance of annual micronutrient monitoring[13] (e.g. vitamin D, iron, calcium and phosphorus) is highlighted in the literature to correct deficits in these patients. While the majority of SA RDs did not regularly assess micronutrient deficiencies, those SA RDs who were concerned mostly considered iron, vitamin D and calcium. In this instance, RDs in Saudi Arabia set the example as almost all their RDs habitually test micronutrient status.[12]

### *Nutritional management*

Dysphagia, GOR and constipation have been highlighted in the literature as the most significant gastrointestinal conditions that can affect feeding in children with CP.[13] Even though dysphagia has been widely described in up to 90% of all children with CP[18], just over a third of SA RDs do not consider the possibility of dysphagia in all their patients. Similarly, the prevalence of GOR and constipation have been reported in up to 70% and 74% of children with CP respectively.[18] The ESPGHAN[13] guidelines' approach to treating constipation is the same as for neurotypical children and is appropriately managed by the majority of SA RDs (80%). Half the SA RDs prescribed probiotics yet this is not included in the ESPGHAN[13] guidelines. A recent review (2020) concluded that although probiotics have a positive effect on the intestinal habitat, there is no benefit on constipation.[19]

The ESPGHAN[13] guideline to initiate enteral feeding only when oral feeding is unsafe, nutritionally inadequate, stressful and prolonged[13] was observed by almost all SA RDs. The guidelines provide recommendations to use certain feeds for four different groups of patients.[13] In this study SA RDs complied with the recommendation to use breast milk, formula or energy-dense infant formula as indicated for infants as well as high-energy feeds for those who are volume restricted. Only one-fifth of SA RDs used the suggested feed for children over one year, namely a standard polymeric feed with fibre. Most chose fibre-free feeds, possibly due to the higher cost of fibre feeds. The recommended use of low-energy feeds with fibre for immobile patients was followed by less than one-fifth of SA RDs. As this type of feed is not commercially available in SA, RDs are faced with adjusting feeds based on what the patient can afford and on what feeds are available, without compromising their patient's nutritional management.

Although the null hypothesis comparing the practices of public- and private-sector SA RDs showed no significant difference in their overall management of children with CP, some individual guidelines differed significantly. The differences in practice are probably in part because these sectors have different structures in SA. The public sector has separate departments[20] that provide allied healthcare services, which include occupational therapy, physiotherapy, speech therapy and dietetics, allowing better networking between the HCPs. The public sector also operates within the confines of standard protocols[21] and a strict budget, while the private sector practises with more management and financial flexibility.

### *Challenges identified by South African registered dietitians*

Unfortunately, most SA RDs face challenges that limit optimal nutritional care. Poor caregiver compliance was reported by almost all SA RDs. Literature shows that families of children with CP may report their practices inaccurately for fear of being judged, to seek approval or to receive compensation,[22] while others overestimate the food consumed as they overlook spillage and vomiting.[18] Compliance may be affected by their children's feeding difficulties[23] or the caregivers' education level, language and cultural barriers.[22,23] Research shows that non-compliance by caregivers of children who had gastrostomy feeding was due to many barriers perceived by caregivers, including the confirmation of permanence of the disability,

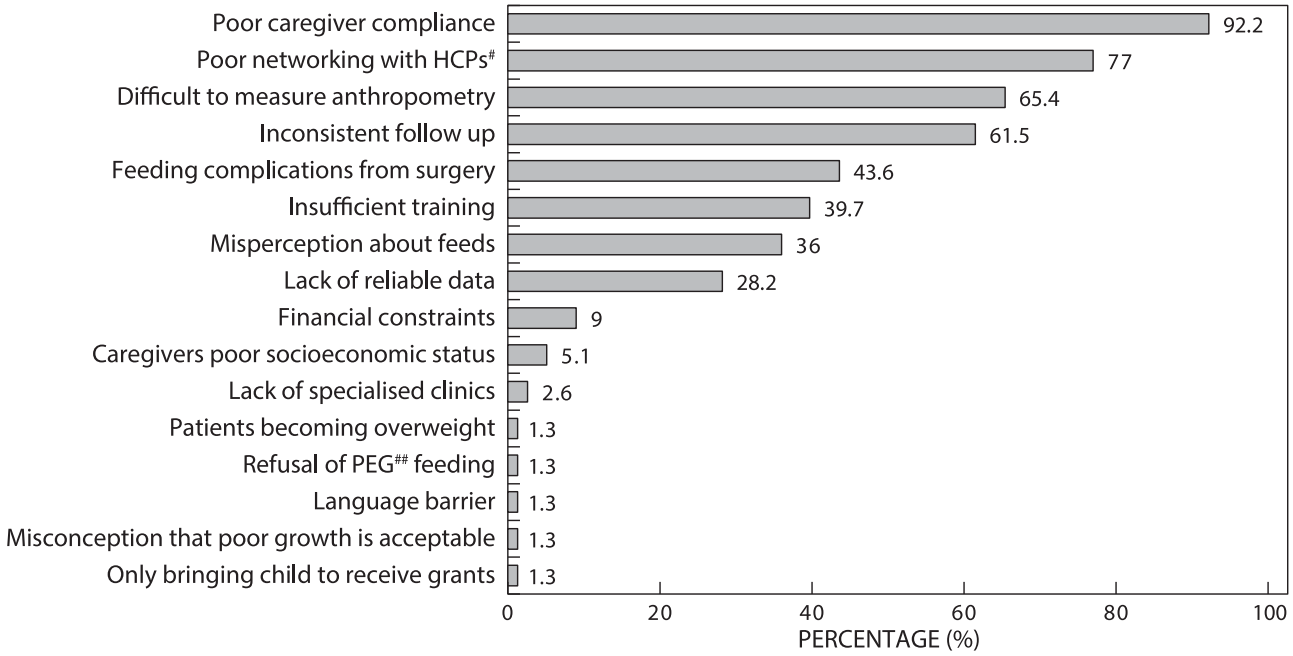


**Figure 1:** Challenges registered dietitians ($n = 78$) face when managing children with cerebral palsy.
Note: # Health care professional; ## Percutaneous endoscopic gastrostomy

fearing discrimination from others and the loss of the nurturing maternal experience of feeding their child orally.[24]

Proper nutritional care is further impeded by insufficient networking between SA RDs and other HCPs. The accomplishment of more than 8 out of 10 SA RDs engaging in an interdisciplinary approach when managing children with CP has been described as beneficial[13] as this leads to the referral of more patients and better dietetic practices.[11,12] Findings from this study are higher than from previous studies reporting that 6 out of 10 dietitians worked as part of a multidisciplinary team including doctors, occupational therapists, speech therapists and physiotherapists.[11,12] Perplexingly, despite SA RDs' involvement in a team, this study showed that more than two-thirds found networking with other HCPs unsatisfactory. Based on findings in the current literature, RDs may enhance networking with HCPs by using web-based networks to improve transparency and quality of care.[25,26]

The most common challenge SA RDs identified with which caregivers struggle regarding the nutritional care of their children was a lack of financial resources. The cost of living is substantial

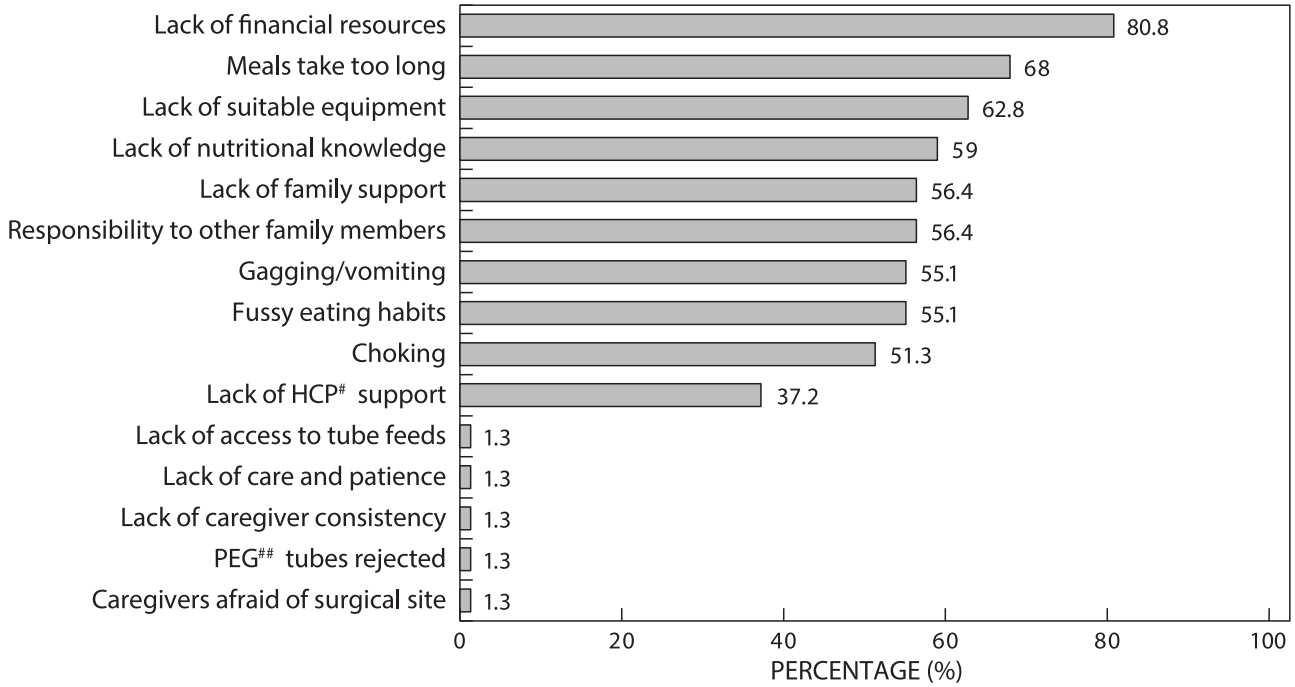


**Figure 2:** Challenges registered dietitians ($n = 78$) perceive caregivers face when supporting their children with cerebral palsy nutritionally.
Note: # Health care professional; ## Percutaneous endoscopic gastrostomy

for people with disabilities as the caregiver needs to provide the basic needs as well as the additional costs needed to care for their disabled child[27] including medical care and therapy, and specialised equipment. In the developing world, this burden falls almost entirely on the family.[28] Mealtime challenges are well documented and include meals taking too long and being stressful because of the child's feeding difficulties due to poor eating and drinking ability, which can cause coughing, vomiting, gagging, drooling and food refusal.[8,28] These challenges highlight the importance of including the guidance of other HCPs to improve the nutritional management of these children. SA RDs' perception that caregivers struggle with lack of support from their families and from HCPs is aligned with findings from an African systematic review[29] that children with CP have limited access to healthcare facilities and HCPs. Furthermore, caregivers are unhappy with the lack of information regarding diagnoses, and its impact on the child and their family.[30]

### *Recommendations*

Improved and updated teaching at tertiary institutions is pivotal to advance the nutritional management of children with CP. The undergraduate dietetic curriculum needs to cover concepts of the prevention and recognition of malnutrition in children with CP as highlighted in this study, multidisciplinary care and early intervention across all levels of health care in SA. Additionally, the curricula of all disciplines relevant to the management of children with CP (including medicine, occupational therapy, physiotherapy and speech therapy) should recognise the importance of interprofessional education and collaborative practice (IPECP) to enhance a holistic approach for the care of children with CP. A unique set of SA nutritional guidelines should be formulated, based on the SA environment and resources, and taking these ESPGHAN[13] recommendations into account. An affordable and appropriate low-calorie, complete paediatric feed rich in fibre should be made available for children with low energy needs.

### *Limitations*

Sample bias may exist due to the small sample size. Data received were on reported practice and not actual practice. The facilities available to the RDs were not taken into consideration. Use of an electronic survey does not allow for probing questions to clarify findings. It is beyond the scope of this study to provide solutions to the problems identified.

## Conclusion

Compared with the ESPGHAN[13] guidelines, although certain practices were well achieved, there were gaps in SA RDs' nutritional management of children with CP, particularly pertaining to anthropometry. The overall practice of publicly and privately practising SA RDs was comparable, apart from a few individual guidelines (being part of a multidisciplinary team, estimating and monitoring certain requirements and the management of GOR) that could be attributed to their different working environments. This study highlights the many challenges SA RDs face that impede the best possible care available to these vulnerable children. It is important to understand and resolve these concerns, which include poor compliance, poor networking with other HCPs and difficulties with measuring anthropometry. Caregivers also need to withstand many obstacles when caring for their children, including financial constraints and difficulties with feeding. Since this study was a descriptive account of the practices of SA RDs, it is suggested that a qualitative study be carried out to determine how to improve current practices by exploring in-depth reasons why certain practices are carried out and how to elevate them.

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