

Measuring Quality of Life in Home Parenteral Nutrition Outpatients is a Complex Art

Research Article

Volume 1 Issue 1- 2021

Author Details

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Article History

Received: August 12, 2021 Accepted: September 22, 2021 Published: September 27, 2021

Abstract

Background: Patients treated with home parenteral nutrition often have impaired quality of life (QoL). The use of QoL measurements, may provide the possibility to prioritize problems between clinician and patient and to monitor response to treatment.

Objective: To find the two tools most suited for assessment of QoL in our HPN-patients. Further, to investigate quality of life, patient's perception of tools, and the sensitivity to hand grip strength (HGS) and internal validity of the preferred tool.

Methods: The iterative multi-method design included document analysis, semi-structured patient interviews, and a questionnaire-based investigation using the two tools. Results were compared to HGS. For statistics, unpaired t-test and Mann-Whitney were used.

Results: EORTC-QLQ-C30 and HPN-QOL address the eight domains found in the 13 patient interviews. Thirty-one patients replied to QOL-questionnaires. Low QoL was found by EORTC-QLQ-C30, General Health (GH)=51.26 (SD±4.28). Using HPN-QOL, QoL was slightly better (GH=69.85 (SD±3.62)). Worst items were employment, sexual function, ability to holiday, fatigue and sleep. Differences between tools were seen for physical function (p=0.00), and fatigue (p=0.02). For the preferred "HPN-QOL" the association between "General Health" and "The physical function score" and HGS were insignificant. Evaluation of internal validity with Cronbach's α test 64.28% were above 0.7.

Conclusion: Eight domains found by interviews were reflected in EORTC-QLQ-C30 and HPN-QOL. Patients preferred the HPN-QOL. QOL was decreased and an ongoing assessment using HPN-QOL seems relevant, even though our measures did not show association with HGS. Internal validity was fair for HPN-QOL.

Keywords: Home parenteral nutrition; Intestinal failure; Quality of life; Patients; Outpatients; HPN-QOL

Introduction

Home Parenteral Nutrition (HPN) is the life prolonging therapy in patients with chronic short bowel syndrome, also known as type III intestinal failure [1-3]. Many issues have been shown to contribute to an overall decreased quality of life (QoL) in HPN-patients, as shown in former studies [4-11]. Potentially life-threatening catheter complications such as severe infections, thrombosis, liver failure and osteoporosis, are pervasive threats to patients' lives and mobility [12-15]. These threats as well as QoL, are influenced by the amount of

infusions per week, as well as the presence of ostomies and physical function [5-8,16]. Furthermore psychosocial complaints, fatigue and social isolation highly affect QoL in HPN-patients [6,8,16-19].

The use of QoL measurements in the outpatient clinical practice setting, provides the possibility to assess changes in QoL. Thereby, the QoL tool can be used to prioritize problems between clinician and patient, facilitate communication, screen for potential problems, identify preferences and monitor changes or response to treatment. They furthermore provide a basis for facilitating the setting of realistic



treatment goals [20]. In a former study, we measured QoL by EQ5D-3L in 50 HPN-patients, in order to find a tool feasible for use in our outpatient setting. We found a decreased QoL in HPN-patients especially in those below age 50, and in dimensions of usual activities and pain/discomfort. The EQ5D-3L was preferred by patients between two tools, as it was found relevant, understandable, and not exhausting for patients to use [19]. Our practical experience however is, that the EQ5D-3L lacks sensitivity for clinical changes, and therefore we were searching for another tool to use. But which tool? There are many options and many validated tools, however the literature points in all directions. The very important issues for us were, that patients could relate to the questions, that they did not find the use of the tool exhausting, and that the tool had been shown sensitive to changes of physical function, treatment changes and HPN education [5,6,8,21–23]. The aim of this study therefore was to investigate QoL with and between the two existing tools most suited for sequential assessment of QoL in our HPN-patients. Furthermore, we aimed to evaluate whether the best rated tool met the requirements for sensitivity and internal validity we seek in a tool in our practice with HPN-patients in the outpatient clinic.

Methods

The design was an iterative multi-method design study, consisting of semi-structured interviews, to clarify the domains that define QoL for our patient cohort. Thereafter, literature search was performed to find the two tools which best fulfill the contents of the found domains, physical function, treatment changes and HPN education. Thereafter we assessed QoL with both of the tools, in a posted questionnaire-based investigation and made a statistical analysis of the data from the two tools each. Finally, using statistics and pragmatic document analysis we evaluated their comparability towards use and sensitivity to physical function respectively. Figure 1 shows the different steps of the study design.

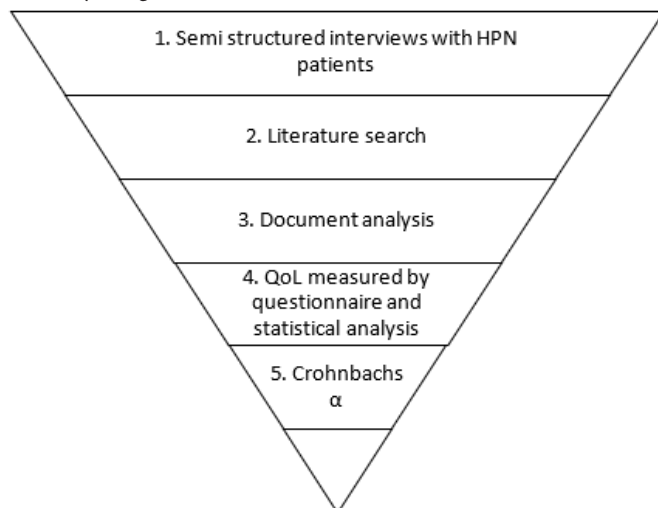


Figure 1: Steps of the “multi-method design”.

Inclusion

For both the qualitative and the quantitative study we included Danish speaking patients >18 years of age, who had received HPN at least four times weekly for a period of > 6 months.

Semi structured interviews

The list of patients planned to meet at the ambulatory was screened by the consultant in charge of the ambulatory. Those patients, who meet the inclusion criteria, were phoned by the Head of Clinical Nutrition Research (last author) who informed the patients about the project and invited them to participate. Those interested were sent written information, which was signed before the interview. The

patients chose the time and setting for the interview. The interviews were constructed as a conversation between the interviewer and the participant, based on a semi-structured interview guide including four open-ended questions, which served as a template for the interviews, striving in particular “*What affects the HPN-patients’ QoL, and what are the most important issues to measure*”. In each interview there was a primary interviewer, who led the conversation, and a secondary interviewer, who made sure all questions in the interview guide were fully covered. This approach was chosen based on the assumption that the primary interviewer would then be able to give full attention to the participant. The interviews were recorded, transcribed verbatim, and finally analyzed for items and domains.

Literature search

Literature was sought for questionnaires regarding QoL in HPN-patients in PUBMED, CINAHL and Google Scholar databases. The search found 15 questionnaires. These were analyzed by thematic document analysis, including the themes found in the patient interviews [24].

QoL questionnaire investigation

All HPN-patients in our local cohort who fulfilled the inclusion criteria, were invited by letter to participate in the questionnaire investigation (n=81). Patients were asked to fill in both questionnaires, and to indicate which of the two questionnaires best suitable for them.

The *EORTC-QLQ-C30* is composed of 30 questions that include 14 physical and psychosocial problem areas. The patient assesses the severity of the problem on a scale of 1 to 4; 1 not at all, 2 a little, 3 some or 4 a lot and the total quality of life on a scale from 1-7. These include five functional scales, three symptom scales, a global health status/QoL scale, and six single items. The *EORTC QLQ-C30* covers 14 problem areas: Physical function, cognitive function, role function, social function, emotional function, pain, fatigue, nausea/vomiting, loss of appetite, shortness of breath, constipation, diarrhea, difficulty sleeping and finances [25,26].

The *HPN-QoL questionnaire* contains 7 multi-item functional scales and 1 single-item functional scale, as well as 6 multi-item and 3 single-item symptom scale. The functional scales include General Health (GH), Ability to Holiday or Travel (HT), Coping (CO), Physical Function (PF), Ability to Eat and Drink (ED), Employment (EM), Sexual Function (SX), and Emotional Function (EF). The symptom or problem scales include Body Image (BI), Immobility (IM), Fatigue (FA), Sleep Pattern (SP), Gastrointestinal Symptoms (GI), other Pain (PA), Presence or Absence of a Stoma (ST), Financial Issues (FI), and Weight (WT). Two questions relate to nutrition teams and the availability of an ambulatory pump for infusion of HPN. A high score represents a good outcome [6,27].

Both scales measure range in scores from 0 to 100. A high scale score represents a higher response level. Thus, a high score for a functional scale represents a high/healthy level of functioning, a high score for the global health status/QoL represents a high QoL, but a high score for a symptom scale/item represents a high level of symptomatology/problems.

Statistical analyses

The statistical analyzes were performed in the Statistical Software Program, STATA version 16. To investigate if there is any difference between the participants under 70 years old, those above 70 years old and between males and females, an unpaired t-test was used, as the population in the compared groups were not related. The unpaired t-test was used when the assumption of normality was met. If data were not normally distributed a Wilcoxon Rank Sum (Mann-Whitney) test was used instead. To investigate whether data were normally distributed, the Shapiro-Wilk test was used.



To investigate significance between the answers from EORTC-QLQ-C30 and the answers from HPN-QOL a paired t-test was used because the groups were related. Paired t-test was used when the assumption of normality was met, while a Wilcoxon Signed Rank test was used if data were not normally distributed. To investigate whether data were normally distributed, the Shapiro-Wilk test was used. The level of significance was set to $\alpha = 0.05$.

For the preferred questionnaire “HPN-QOL” an analysis of the association between “The General Health Score” and “The physical function score” and Hand Grip Strength (HGS) was made. Finally, a Cronbach’s α test was made on the scales containing more than one item (multi-item scales), to assess the internal consistency within each domain of the questionnaire.

Results

Interviews

A total of 13 patients (nine females, mean age 67,9) were interviewed.

Table 1: Domains and the items it contains from the semi-structured interviews.

Gastro-intestinal Problems	Sleep	Symptoms/ complications	Social/family life	Emotional life	Independency	Body image	Physical function
Diarrhea	Interrupted sleep	General health	Friends/ Family -Decreased social life	Supportive spouse	Lack of Travelling and holidays away	Odor	Immobility
Abdominal pain	Difficulty falling asleep	Reduced concentration	Keeping and fulfilling a job	Decreased mental health	Tied to HPN	Visible disease	Reduced functional level
Stomal output	Nocturia	Pain	Must stay near a toilet	Support from hospital staff	Tied to house	Stoma	Lack of sport activities
Nausea		Underlying disease	Lack of spare time/ time alone	Stress	Lack of independency and freedom	Catheter	Walk outdoor
Reflux		Risk of hospitalization	Difficulty planning with HPN	Dissapoint-ment to family and friends	Day off PN	Dress up	Reduced strength
		Catheter related infections	Everyday activities/ work	Living with limitations		Weight	Fatigue/ low energy level
			Joy of eating	Disease controls life			Not able to go swimming
			Fulfilling a role	Lack of spontaneity			

Questionnaire investigation

In total 81 patients received an invitation letter for validation and test of QoL instruments. Thirty-one patients returned the questionnaires and of those 21 (13 females, mean age 69,5, range 30-83) had their latest hand grip strength tested within the past year. Most patients chose the HPN-QOL questionnaire as suiting them best. Out of 31 patients, 16 chose the HPN-QoL, nine chose the EORTC-QLQ-C30, and six did not specify which questionnaire they preferred.

By the EORTC-QLQ-C30 patients scored a low general QoL. For general function, especially cognitive, emotional and social functioning was low. For general symptoms, fatigue, insomnia, pain, loss of appetite and diarrhea, were the most pronounced factors affecting QoL negatively. Compared to the background population, “all cancer-patients”, our participants scored worse on all parameters besides “constipation”, however standard deviations were much more

In all, 50 items were extracted from the interviews and these were gathered into nine domains. These were Gastrointestinal problems, Sleep, Symptoms/complications, Social/family life, Emotional life, Independency, Body image and Physical function. These were included in the search for QoL tools as described in “methods”. Domains and items are seen in Table 1.

Literature search

The 15 found questionnaires were analyzed with content document analysis and the domains compared to the domains identified in the literature search and the interviews. The four questionnaires found most comparable with the found domains from the literature study and the semi-structured interviews, were chosen for further analysis. The questionnaires were examined for availability, validation in the original population and for the domain “physical function” which had to be present, as these were pre-defined criteria. Two questionnaires HPN-QOL© [27] and EORTC-QLQ-C30 [26] met the requirements.

narrow in our population [25]. The mean values of the results from the EORTC-QLQ-C30 are seen in Table 2.

By the HPN-QOL general health was fair but not good, by 69.85 (SD 3.62). Worst functional scale items were “Employment”, “Sexual function” and “Ability to holiday”. For “Employment”, “Sexual function” and for symptom scales besides “body image”, our patients felt better than the comparable studies [6,27]. Patients felt support by their Nutrition Team scoring 87.50 (SD 3.89). The mean values of the results from the HPN-QOL is seen in Table 3.

No significant difference was seen between males and females in any of the function scales, symptom scales or general QoL measured by the EORTC-QLQ-C30 (Table 4).

Furthermore, there was no significant difference between the groups under and above 70 years old in any of the function scales, symptom scales or general QoL measured by the EORTC-QLQ-C30 (Table 5).



Table 2: The mean values of the results from the EORTC-QLQ-C30 Questionnaire.

EORTC-QLQ-C30 (n=31)	Mean (SD)
Global Health Status/QoL	51.26 (4.28)
General Function	
Physical	67.53 (4.92)
Role	56.37 (6.37)
Emotionel	29.80 (5.22)
Cognitive	21.21 (4.49)
Social	45.45 (6.04)
General Symptoms	
Fatigue	45.79 (5.61)
Nausea/Vomiting	27.96 (5.32)
Pain	37.75 (6.80)
Dyspnea	22.55 (5.02)
Insomnia	38.24 (6.46)
Appetite Loss	38.24 (7.06)
Constipation	12.12 (4.55)
Diarrhea	34.34 (6.24)
Financial Problems	16.16 (5.25)

All values are means

Table 3: The mean values of the results from the HPN-QOL Questionnaire.

HPN-QOL (n=31)	Mean (SD)
General Health	69.85 (3.62)
Function Scales/items	
Ability to Holiday/Travel	33.46 (2.48)
Physical	53.94 (2.38)
Coping	50.16 (2.47)
Ability to Eat/Drink	47.22 (2.62)
Employment	44.70 (5.84)
Sexual Function	40.48 (11.42)
Emotional Function	48.84 (3.19)
Home Parenteral Nutrition Items	
Nutrition Team	87.50 (3.89)
Ambulatory Pump	66.67 (8.56)
Symptoms Scales/Items	
Body Image	38.90 (3.88)
Weight	59.65 (6.54)
Immobility	38.54 (4.49)
Fatigue	63.13 (5.17)
Sleep Pattern	62.67 (5.21)
Gastrointestinal Symptoms	61.27 (2.59)
Pain	42.47 (3.17)
Presence of Stoma	43.75 (5.00)
Financial Issues	NA

All values are means

Table 4: Differences in the results between male and female from the EORTC-QLQ-C30.

QLQ-C30	Male (n=10) Mean (SD)	Female (n=21) Mean (SD)	P-value
Global Health Status/QoL	54.17 (9.96)	50.00 (4.51)	0.66
General Function			
Physical	72.67 (8.16)	65.08 (6.22)	0.48
Role	53.03 (13.82)	57.98 (6.94)	0.72
Emotionel	33.33 (12.85)	28.26 (5.21)	1.00**
Cognitive	23.33 (10.89)	20.29 (4.56)	0.82**
Social	46.67 (13.56)	44.93 (6.58)	0.90
General Symptoms			
Fatigue	43.33 (13.19)	46.86 (5.88)	0.78
Nausea/Vomiting	28.03 (6.79)	27.78 (8.33)	0.80**
Pain	33.33 (14.27)	42.03 (7.69)	0.56
Dyspnea	33.33 (11.89)	17.40 (7.98)	0.30**
Insomnia	51.52 (13.75)	36.23 (6.92)	0.27
Appetite Loss	39.99 (12.57)	37.68 (8.72)	0.91
Constipation	15.15 (8.24)	10.61 (5.54)	0.56**
Diarrhea	30.00 (11.60)	36.23 (7.53)	0.65
Financial Problems	33.33 (14.70)	12.12 (4.68)	0.21**

** Wilcoxon Rank Sum (Mann-Whitney) Test is used

Table 5: Differences in the results between the participant under 70 years old and above 70 years old from the EORTC-QLQ-C30 Questionnaire.

EORTC-QLQ-C30	<70 years (n=16) Mean (SD)	≥70 years (n=15) Mean (SD)	P-value
Global Health Status/QoL	50.00 (5.64)	52.78 (6.74)	0.75
General Function			
Physical	62.59 (6.40)	74.36 (7.58)	0.25
Role	48.25 (7.85)	66.67 (10.16)	0.15
Emotionel	30.09 (7.38)	29.44 (7.58)	0.97**
Cognitive	21.30 (5.52)	21.11 (7.54)	0.77**
Social	49.08 (7.44)	41.11 (10.00)	0.52
General Symptoms			
Fatigue	50.00 (7.03)	40.74 (9.12)	0.42
Nausea/Vomiting	30.56 (7.03)	24.36 (8.36)	0.53**
Pain	43.52 (9.25)	34.44 (10.22)	0.52
Dyspnea	21.05 (6.84)	24.44 (7.61)	0.63**
Insomnia	47.39 (8.95)	33.33 (9.20)	0.29
Appetite Loss	40.35 (9.73)	35.56 (10.52)	0.74
Constipation	18.52 (7.73)	4.44 (3.03)	0.23**
Diarrhea	37.04 (8.89)	31.11 (8.89)	0.64
Financial Problems	29.17 (9.56)	6.67 (3.56)	0.09**

** Wilcoxon Rank Sum (Mann-Whitney) Test is used.

For HPN-QOL no significant differences were found between males and females in general health, any of the function scales/items, Home Parenteral Nutrition item or symptom scales/items. Furthermore, there was no significant difference between the groups under and above 70 years old in any of the function scales/items, Home Parenteral Nutrition item or symptom scales/items measured by the HPN-QOL Questionnaire.



A difference between the groups under and above 70 years old was shown in General Health measured by the HPN-QOL Questionnaire. The mean general health among the participant under 70 years old was 76.25 and the mean general health among the participants above 70 years old is 60.72. This is a difference of 15.53 ($p=0.03$), indicating a much better health in those younger.

When comparing the answers from the EORTC-QLQ-C30 and the HPN-QOL there are some differences. The general health measured by HPN is 66.67 when the general health measured by EORTC is 51.85. This is a significant difference of 14.82 ($p = 0.03$). These results can be seen in Table 6. The mean physical function measured by HPN-QOL is 53.94 whereas the physical function measured by the EORTC-QLQ-C30 is 67.53. This is a difference of 13.59 ($p = 0.00$). Furthermore, a significant difference was seen between the fatigue symptom measured by the HPN-QOL and the EORTC-QLQ-C30, where the mean score of fatigue is 65.56 measured by HPN-QOL and 45.93 measured by EORTC-QLQ-C30. This is a difference of 19.63 ($p = 0.02$). However, compared to reference values for both tools, the patients in this study scored 11 points higher for both tools compared to others.

Table 6: Differences between the results from HPN-QOL and EORTC-QOL-C30.

	HPN Mean (SD)	EORTC Mean (SD)	P-value
General Health			
General Health/ Global Health Status	66.67 (5.35)	51.85 (6.16)	0.03*
Function Scales/Items			
Physical Function	53.94 (2.38)	67.53 (4.92)	0.01* **
Emotional	48.84 (3.19)	29.80 (5.22)	0.20**
General Symptoms			
Fatigue	65.56 (8.37)	45.93 (8.25)	0.02*
Sleep Pattern/ Insomnia	64.10 (8.82)	51.28 (11.70)	0.29
Pain	43.75 (4.00)	39.58 (9.96)	0.70
Financial Problems	NA	16.16 (5.25)	NA

* Indicates significance

** Wilcoxon Signed Rank Test is used

There was no significant difference between the answers from EORTC-QLQ-30 and the HPN-QOL in the emotional scales, sleep patterns/insomnia or the symptoms of pain. Financial items are left out of analysis in the HPN-QOL, due to missing variables.

HPN-QOL associations to strength and internal validity

For the preferred questionnaire “HPN-QOL” the association between “General Health” and HGS was insignificant ($p = 0.075$) as well as for the “The physical function score” ($p = 0.264$).

Twenty scales were present in the HPN-QOL and of those it was possible to calculate Cronbach’s α test on 14. The scales of Cronbach’s α differed from -0.022 to 0.967. Of these scales, 64.28% were above lowest acceptable value which is 0.7 for acceptable internal validity. Thus, the 64.28% could be considered reliable regarding internal consistency.

Discussion

In this iterative multi-method design study, we aimed to investigate QoL with and between the two existing tools most suited for sequential assessment of QoL in our HPN-patients. Furthermore, we aimed to evaluate whether the tool found superior, lives up to the sensitivity and internal validity we want for using a QoL tool in our practice with HPN-patients in the outpatient clinic.

The semi-structured interviews found eight main domains including 50 items, significant for the specific trouble to QoL in this population. These are all in accordance with former studies, however financial issues were not pronounced, as seen in other studies. This might be due to the safety of the Danish healthcare and financial system, which covers expenses related to treatment and pension or social maintenance [5,9–11,23,28–30]. Literature search gave 15 questionnaires aimed QoL in HPN, however only two of them passed the bar of fulfilling patients requirements found by the qualitative interviews, and included a measure of physical function. This is quite interesting, since again, our qualitative findings are in line with others, and being able to keep up physical performance is highly rated in all qualitative studies.

Overall our patients scored low QoL with the EORTC-QLQ-C30, compared to reference values from the target population, however there was a much higher standard deviation to the reference values, than to our small sample of patients [25]. The tool is aimed at cancer patients, and reference values found in the literature, may thus include patients who are at the beginning of treatment, as those who are in rehabilitation as well as palliative care patients. None of our patients have active cancer, however about 20% of our patients had treatment to cancer, including surgery and/or radiotherapy, as the underlying disease which led to short bowel syndrome/intestinal failure. We only included patients who were treated with HPN for at least six months, and thus somewhat experienced, however we did not aim specifically at “stable” patients. When compared to the HPN-QOL, which our patients felt most aligned with, there seems to be something not quite comparable. Even though both scales measure 0-100, visible differences are found within measures of the same i.e. physical function, emotional wellbeing and fatigue. Whether “General health” (HPN-QoL) and “Global QoL” (EORTC-QLQ-C30) as the overall scores are expressions of the same, remains to be answered, but it is possible that this can affect the significant difference of mean values between “General Health” and “Global QoL”.

The majority of our patients chose HPN-QOL as the tool they found most relatable, however this gives no indication of why QoL is higher by this tool than by the other. Since no ideal reference values are found, we can compare only with those of the founding study and one recent larger study from 2019 including 699 participants from 14 countries [6]. Compared to those, our patients are more alike, ours feeling slightly better in some items, including physical function, employment and sexual function, while worse in others like emotional function. Still, our sample is very small, and standard deviations very small compared to the compared population.

The small sample may also provide the lacking association to HGS as the measure for physical function, but since we are quite keen on this association, we need to do the study on a larger sample. We have however decided to move forward with HPN-QOL, due to patients preferring this tool, it is in line with our qualitative results, and has shown sufficient internal validity.

Conclusion

Eight domains impacting QoL among HPN-patients were found by qualitative interviews. These domains were reflected in the tools EORTC-QLQ-C30 and HPN-QOL. Patients preferred the HPN-QOL and measures of QoL were better using HPN-QOL compared to EORTC-QLQ-C30. Still quality of life in our HPN patients is decreased and an ongoing assessment using HPN-QOL in our outpatient clinic seems relevant, even though our measures did not show association to physical strength measured by hand grip strength. Internal validity was fair for HPN-QOL.

Acknowledgement

The authors in the present study would like to thank our HPN-patients for their time and efforts in this study.



Conflict of Interest

The authors declare to have no conflicts of interest for this study.

Funding

None for this study.

Highlights

- a. Gastrointestinal problems, Sleep, Symptoms/complications, Social/family life, Emotional life, Interdependency, Body image and Physical function were the core items to be addressed for a quality of life tool to be relevant to the interviewed HPN-Patients.
- b. A tool for QOL evaluation may be used as a guide for the efficacy of care but should not replace the individual goals set in the dialogue with the patient.
- c. HPN-QOL was found to be the best tool, however it was not sensitive to physical strength, which interviews revealed as important for being self-sufficient and thus having a better quality of life.

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