

Original article

Attitudes and expectations of patients on home parenteral nutrition towards eHealth: A multicenter survey



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SUMMARY

Background & aims: Advances in technology enable patients on home parenteral nutrition (HPN) to manage their treatment more independently and safely. eHealth is a promising application of electronic means in healthcare, aimed at improving and simplifying processes and connecting the different parties involved. A thorough understanding of the attitudes and expectations of patients on HPN towards eHealth is a prerequisite for a successful implementation. However, to the best of our knowledge, such a survey preceding the implementation of HPN specific eHealth care has never been conducted. The objective of this preliminary survey is the acquisition of insights on the attitudes and expectations of patients on HPN towards eHealth. Resulting findings then serve as the basis for the design of an eHealth platform to facilitate communication among those involved in HPN care, improve the HPN management, and safeguard and monitor the treatment.

Methods: We conducted a survey on the attitudes and expectations of patients towards an envisioned eHealth platform for HPN. Patients were recruited from large Swiss hospitals by their treating physician or directly by the research team. The surveys were conducted between September 2020 and October 2021 by structured personal interviews based on a questionnaire.

Results: We included 35 patients on HPN (21 [60%] females) treated in ambulant care of 4 hospitals. They had a median (interquartile range) age of 55 (18) years and a median (interquartile range) duration of parenteral nutrition of 1.3 (3.1) years. Most patients (n = 30, 86%) were equipped with a smartphone, tablet, or computer and 22 (63%) used apps and rated themselves as proficient with the corresponding digital device. A majority of patients rated the following aspects and features of the platform as important: Data collection and storage (n = 29, 83%), checklists for PN, catheter, and infusion pump handling (n = 28, 80%), video instructions (n = 27, 77%), and videoconferencing with physicians (n = 25, 71%). Most patients (n = 26, 74%) were willing to enter data into the platform themselves. The type of data to be entered should be defined on an individual basis.

Conclusions: Patients on HPN are open to videoconference consultations and using an eHealth platform. Two-thirds have the necessary technical skills including suitable digital devices for an eHealth care. We identified key features of an eHealth platform to improve HPN management.

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Abbreviation: HCP, healthcare professional; HPN, home parenteral nutrition; IQR, interquartile range; NST, nutrition support team; PN, parenteral nutrition.

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1. Introduction

For patients unable to meet their dietary requirements via oral and enteral routes, parenteral nutrition (PN) is a life-saving therapy and, if PN is required for long-term care, can be provided outside

hospital settings as home PN (HPN) [1,2]. Few patients require HPN and the prevalence varies widely between countries, ranging from about 5 to 50 cases/million/year, with increasing tendency [3–6].

HPN is a challenging treatment for patients, their relatives and healthcare professionals (HCPs), requiring a multiprofessional and multidisciplinary approach [3,7]. The aseptic preparation and administration of PN through a central venous catheter at home is a difficult and critical task that needs to be rigorously trained, as non-compliance can have severe consequences, such as catheter-related, infectious, and metabolic complications [8]. Moreover, long-term monitoring and close collaboration between patients, their relatives and caregivers, and a multiprofessional nutrition support team (NST) is required [7–9]. An eHealth approach for HPN presents a novel and promising opportunity for keeping all parties involved up to date and for improving patient outcome.

eHealth is an umbrella term covering all electronic health services that employ electronic means to improve processes in the healthcare system and to connect the involved persons [10]. The World Health Organization defines eHealth as the “[...] use of information and communications technologies in support of health and health-related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research” [11].

Among the applications of eHealth is telemedicine, i.e. the delivery of health care services where patients and providers are separated by distance, such as through a telephone or videoconference consultation [12]. Videoconference consultations can deliver more frequent and timely health care to patients with chronic conditions at a distance, thus improving access to healthcare [13]. A second application is remote patient monitoring to detect clinical or technical complications at an early stage. Electronic data processing and analysis may automatically alert healthcare providers to out-of-range values, avoiding delays in interventions [13]. Finally, eHealth may improve patient education and digital HPN peer-support groups can be beneficial for quality of life, depression scores and prevention of catheter-related infections [14].

It is well known that the effectiveness of eHealth depends on several factors, including those related to the study population, e.g. disease severity and progression, the healthcare provider and the healthcare system [13]. However, attitudes and expectations of HPN patients not yet familiar with an eHealth intervention are poorly explored. Their unique health situation likely has a substantial influence on their attitudes and expectations in comparison with the population average.

We aimed to explore patients’ attitudes and expectations towards eHealth before designing a national eHealth platform for HPN patients.

2. Materials and methods

We developed a questionnaire for the survey on the attitudes and expectations of HPN patients towards an eHealth platform. Nutritional scientists, physicians, and pharmacists specialized and experienced in (H)PN were involved in the creation of the questionnaire. We tested the questionnaire with one HPN patient. After minor adaptations, the final questionnaire consisted of 18 questions. Following a short section on basic demographic characteristics and the PN regimen, the remainder was concerned with acquiring information on the use of electronic media and obtaining ratings on suggested features for an envisioned eHealth platform for HPN patients. The questionnaire is included in the supplementary materials.

We recruited HPN patients from four large hospitals (University Hospitals Bern and Zurich; Cantonal Hospitals St. Gallen and

Table 1
Baseline characteristics.

Patients, N	35
Patients per hospital, n (%)	
Inselspital, Bern University Hospital	24 (69)
University Hospital Zurich	5 (14)
Cantonal Hospital St. Gallen	5 (14)
Cantonal Hospital Lucerne	1 (3)
Females, n (%)	21 (60)
Age in years, median (IQR)	55 (18)
PN regimen, median (IQR)	
PN duration in years	1.3 (3.1)
Cyclic PN frequency in nights per week	7 (2.5)
Responsible staff involved in HPN care, n (%)	
Hospital physician	34 (97)
General practitioner	5 (14)
Home care nurse	22 (63)

Abbreviations: HPN, home parenteral nutrition; IQR, interquartile range.

Lucerne). The investigators conducted the interviews in person or via telephone between 14 September 2020 and 22 October 2021.

Statistical analysis was performed using R (R Core Team, 2021) [15], version 4.1.2. We used medians and interquartile ranges (IQR) or sizes of a subsample (n) and percentages. To test for subgroup differences of categorical variables we used the Person's Chi-squared test. A p -value $\leq .05$ was considered statistically significant. No data were excluded and missing data were not imputed.

The employment of an anonymous questionnaire (i.e., without patients’ names or dates of birth), renders any backtracing of responses to patients impossible. The Ethics Commission of the Canton of Bern confirmed that an ethical approval was not required, as it is not in the scope of the Human Research Act, Art. 2, para. 1 (BASEC-Nr: Req-2021-00090).

3. Results

We conducted the survey with 35 patients from 4 hospitals treated by 5 different specialists in nutritional medicine. Table 1 shows the baseline characteristics.

Table 2 shows the number of patients meeting given prerequisites for the use of an eHealth platform. Patients below the age of 60 rated themselves significantly more proficient with digital devices than patients aged 60 years or older (the ratings were: 17 [81%] very/rather proficient, 2 [10%] neutral, and 2 [10%] rather not/not at all proficient in the age group <60 years vs. 5 [36%], 1 [7%], and 8 [57%] in the age group ≥ 60 years, respectively, $p = .009$).

A total of 15 patients (43%) found it burdensome to go to the hospital for consultations regarding HPN, while 17 (49%) did not.

Table 2
Prerequisites for eHealth.

	n (%)
Owning digital devices	
Smartphone	27 (77)
Computer	23 (66)
Tablet	16 (46)
Cell phone without internet capability	8 (23)
Using apps	22 (63)
Self-rated skills in the use of digital devices	
Very/rather proficient	22 (63)
Neutral	3 (9)
Rather not/not at all proficient	10 (29)
Restrictions to using digital devices	
No impairments	32 (91)
Visual impairments	1 (3)
Hearing impairments	1 (3)
Lack of motor/coordination skills	1 (3)

Table 3
Differences in selected survey responses according to duration of parenteral nutrition and age.

	PN duration	Age
	<6 vs. ≥6 months	<60 vs. ≥60 years
Found it burdensome to go to the hospital for HPN consultations	36% vs. 46%	43% vs. 43%
Found in-person contact with the treating physician important	100% vs. 75%	71% vs. 100%
Rated the following eHealth platform features as important:		
Data collection and storage	91% vs. 79%	86% vs. 79%
Checklists for PN, catheter and pump handling	82% vs. 79%	86% vs. 71%
Video instructions	82% vs. 75%	86% vs. 64%
Videoconferencing with physicians	64% vs. 75%	67% vs. 79%

Abbreviation: (H)PN, (home) parenteral nutrition.

The majority of patients (n = 25, 71%) would attend videoconference consultations, with in-person contact with the treating physician nevertheless being important to 29 patients (83%). Table 3 shows differences according to PN duration and age.

Figure 1 shows how many of the patients considered the suggested eHealth platform features important and the ratings of the four most important features according PN duration and age are shown in Table 3.

Data security was important to 27 patients (77%) and ease of use to 26 (74%). For the data collection and storage, a majority (n = 26, 74%) would enter data into the platform themselves, 5 (14%) would prefer someone else to enter data, and 4 (11%) would not enter data at all. Figure 2 shows to whom the patients would give data access.

Figure 3 shows the patients' rating of the importance of the suggested data entries. When asked what they were missing from our suggested features and data entries, 3 patients (8.6%) independently stated that they would welcome functionality for tracking mental health and quality of life. One-fourth of patients (n = 9, 26%) reported interest in connecting with other patients.

4. Discussion

The most important suggested feature of the envisioned eHealth platform was data collection and storage. Digital data entry for

remote monitoring is well structured, simple and regularly backed-up. Centrally stored data are accessible to the patient, involved caregivers and the NST, which facilitates communication and allows for rapid information exchange to keep everyone up to date. All HCPs in the NST should have access to the platform; however, access to specific data must be regulated on an individual basis and limited to the minimum necessary. Patients considered almost all the suggested data entries to be important, given that the treating NST requires them for treatment monitoring. This demonstrates the importance of customizability of the eHealth platform, e.g. through selective feature activation and data entry relevant for the treatment of a specific patient.

A recent study suggests the need for improvement in patient education and training, highlighting their importance for aseptic handling, as patients who self-administer PN are at higher risk for infection than patients cared for by home nurses [3]. Patients in our survey also recognize an opportunity for the application of eHealth in patient education and thus rated checklists for PN, catheter and pump handling, as well as video instructions as important.

Another feature central to an eHealth platform was videoconferencing. Videoconference consultations facilitate access to PN specialists for some patients at a distance. In Switzerland, HPN programs are not implemented in all hospitals and the management of patients varies widely [3]. As a result, not all patients have

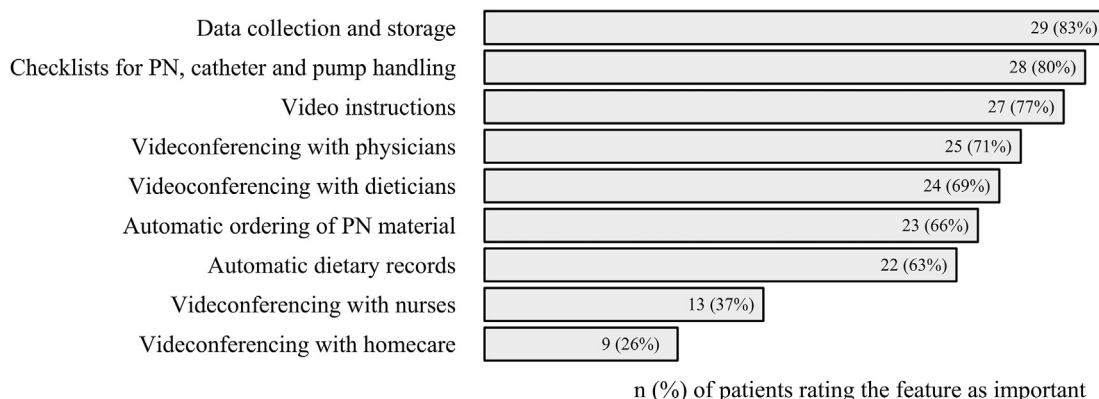


Fig. 1. Patients' rating of the importance of suggested features of the eHealth platform. Abbreviation: PN, parenteral nutrition.

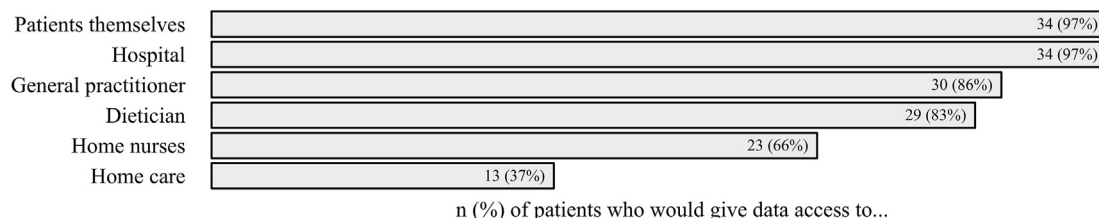


Fig. 2. Number (percentage) of patients who would give data access to those involved in HPN care.

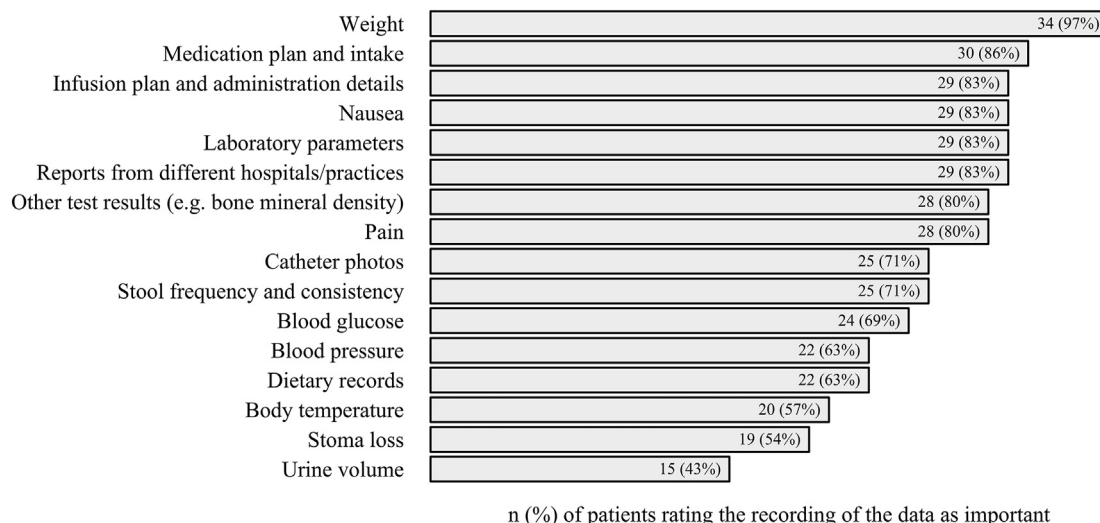


Fig. 3. Patients' rating of the importance of suggested data to be recorded in the eHealth platform.

access to a specialized hospital in their proximity and HPN patients have unequal access to short-term care and prompt diagnosis. Due to the lower barriers of videoconference consultations, more frequent contact between patients and PN specialists is possible, which has the potential to prevent complications in general and increase the treatment quality and safety. Furthermore, high-risk patients do not need to go to the hospital as often, which, besides saving time, money and travel, also reduces the risk for nosocomial infections. Most importantly, appropriate treatment can be provided more quickly due to the time saved.

A number of patients suggested mental health tracking as an additional feature. HPN monitoring does indeed include mental health tracking, as depression and anxiety are prevalent issues reported by patients receiving HPN [16]. We therefore intend to include functionality for the tracking of mental health in the envisioned eHealth platform. For instance, the implementation of questionnaires on quality of life [17] and general mental health (e.g. Optum® SF-36v2® Health Survey) would facilitate monitoring patients' emotional well-being and allow HCPs to act promptly upon any significant changes. Regular videoconferences would provide HCPs with the opportunity to discuss changes in the well-being of their patients in a timely manner.

Smith and colleagues provided HPN patients affected by benign short bowel disorders with tablets [18]. After two videoconference appointments over a median interval of two months, patients, family members, and HCPs evaluated the appointments and reported which tasks the tablets were used for. The majority found the videoconference appointments convenient and of comparable quality of care to an in-person meeting. Patients reported sending photos of their catheter and 24-h urine collection containers to their physicians. Patients also used the tablet to track their medication, laboratory values, medical supplies, and fluid intake and output [18]. Similarly, the patients in our survey considered it important to access the medication list, track medication intake and PN administration as well as laboratory values, among other data. Smith and colleagues also delivered synchronous group videoconferencing sessions via tablets and uploaded additional material (written information, forms, illustrations and graphics) to mobile devices [19]. Patients highly valued the group videoconferencing sessions [19], while only a minority of the patients in our survey reported interest in group sessions.

Almost two-thirds of patients, and 81% of patients below the age of 60, had proficient digital skills, but a third did not use apps on

smartphones or tablets. Nevertheless, HPN patients valued in-person contact with their physician and about half of patients find going to the hospital for follow-up visits not burdensome. Patients who had already had PN for more than 6 months tended to find it more burdensome to go to the hospital for consultations and in-person contact with their physician was less important to them. Consequently, they rated the feature video conferencing with physicians more important. Patients over the age of 60 considered in-person contact to be highly important. The use of an eHealth platform among this age group is thus likely to be limited to other features. These results confirm the appeal of a hybrid solution of in-person contact and videoconference consultations to most patients while the data entry could be used both for in-person and online consultations. Data collection was important for all patients, but seems to be even more important for patients who have PN for less than 6 months. Which services of eHealth care are beneficial for a patient must therefore be decided on the basis of individual needs and factors, which in turn shows the importance of customizability of a platform.

Our survey population had a similar age and gender distribution as a previous study investigating a representative Swiss adult HPN cohort [3]. Although the absolute sample size of our survey was rather small, it corresponds to about 15% of the Swiss HPN population (241 HPN patient cases in 2015 [6]). Therefore, we conclude that our results are well generalizable to the Swiss HPN population.

While our survey focused on the prerequisites for eHealth from the patients' perspective, Zachrisson, et al. recently identified physician characteristics associated with the transition to eHealth care [20]. They found that female (odds ratio [OR], 1.23; 95%CI, 1.06–1.44), behavioral health (OR, 2.92; 95%CI, 2.11–4.04), and primary care (OR, 1.69; 95%CI, 1.36–2.09) physicians had greater odds of being early adopters of eHealth, while patient characteristics were less strongly associated with physicians' adoption of eHealth.

To the best of our knowledge, this is the first survey on the attitudes and expectations of HPN patients towards eHealth in a more holistic approach and as a tool to better define a subsequent eHealth platform design. However, previous studies conducted videoconference appointments with HPN patients and retrospectively assessed the satisfaction and use of digital tools provided to the patients. Patients were generally satisfied with videoconference sessions for consultations and education [18,19,21,22]. This is in line with the expectations of patients in our survey, in which checklists

and video instructions were rated as even more important than videoconferencing with HCPs.

A limitation is that the survey was conducted through an interview, risking interviewer bias and acquiescence bias. However, topic complexity prevented some patients from completing the survey without the assistance of an interviewer. A further limitation is that the questionnaire was tested on one patient only.

Through this preliminary survey of a representative sample of Swiss HPN patients, we better understand HPN patients' attitudes and expectations towards eHealth. Patients are open to videoconferencing consultations and eHealth care, which hold the potential to facilitate communication and improve efficiency and flexibility in contact with HCPs. Overall, two-thirds, and especially patients under the age of 60, have good technical skills and possess appropriate digital devices. To optimally target the benefits for patients receiving critical long-term care such as HPN, centralized data collection and storage, checklists and video instructions, and videoconferencing with HPN specialists are key features of an eHealth platform. Furthermore, additional functionality for mental health tracking was requested.

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Statement of authorship

Katja A. Schönerberger: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Validation, Visualization, Writing - original draft. **Emilie Reber:** Conceptualization, Investigation, Methodology, Writing - review & editing. **Duy-Tan Vu:** Investigation, Writing - review & editing. **Claudia Krieger:** Resources, Writing - review & editing. **Philipp A. Gerber:** Resources, Writing - review & editing. **Raphaela Muri:** Writing - review & editing. **Valentina V. Huwiler:** Writing - review & editing. **Stefan Mühlebach:** Conceptualization, Funding acquisition, Methodology, Supervision, Writing - review & editing. **Michèle Leuenberger:** Conceptualization, Methodology, Resources, Writing - review & editing. **Zeno Stanga:** Conceptualization, Methodology, Funding acquisition, Resources, Supervision, Writing - review & editing.

Conflict of interest statement

The authors have no conflicts of interest to declare.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.clnesp.2022.09.026>.

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