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ORIGINAL ARTICLE

Evaluation of the Claria sharesource system from the perspectives of patient/caregiver, physician, and nurse in children undergoing automated peritoneal dialysis

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Abstract

Background Automated peritoneal dialysis (APD) is increasingly preferred worldwide. By using a software application (Homechoice with Claria sharesource system (CSS)) with a mod-M added to the APD device, details of the home dialysis treatment become visible for PD nurses and physicians, allowing for close supervision. We aimed to evaluate the perceptions of patients/caregivers, PD nurses, and physicians about the advantages and disadvantages of CSS.

Methods Three different web-based questionnaires for patients/caregivers, nurses, and physicians were sent to 15 pediatric nephrology centers with more than 1 year of experience with CSS.

Results Respective questionnaires were answered by 30 patients/caregivers, 22 pediatric nephrologists, and 15 PD nurses. Most of the nurses and physicians (87% and 73%) reported that CSS improved patient monitoring. A total of 73% of nurses suggested that CCS is not well known by physicians, while half of them reported reviewing CSS data for all patients every morning. Sixty-eight percent of physicians thought that CSS helps save time for both patients/caregivers and healthcare providers by reducing visits. However, only 20% of patients/caregivers reported reduced hospital visits. A total of 90% of patients/caregivers reported that being under constant monitoring made them feel safe, and 83% stated that the patient's sleep quality improved.

Conclusions A remote monitoring APD system, CSS, can be successfully applied with children for increased adherence to dialysis prescription by giving shared responsibility and may help increase the patient's quality of life. This platform is more commonly used by nurses than physicians. Its potential benefits should be evaluated in further well-designed clinical studies with larger patient groups.

Keywords Peritoneal dialysis · Remote monitoring · Children · Quality of life

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Introduction

Peritoneal dialysis (PD) is the dialytic modality of choice in children, particularly in young ones [1], and the majority of these children are on automated PD (APD) [2]. Peritoneal dialysis as a home dialysis modality offers more independence and autonomy to patients when compared with in-center hemodialysis (HD). However, the compliance of the patient with the physician's prescriptions while at home is essential for the success of PD [3].

Recently developed remote-controlled APD systems and particularly online systems such as the Claria sharesource system (CSS) improve patient monitoring by providing active monitoring of clinical parameters such as ultrafiltration (UF), blood pressure (BP), and body weight (BW). Treatment incompatibility such as early termination of PD and not waiting for the drainage period can be detected and proactively eliminated by using CSS data. Additionally, compliance with other medical treatments also increases with the active participation of patients in their treatment at home [4]. It is considered possible that this system will achieve its main goal of harmonious work between the patient/caregiver, dialysis nurse, and physician.

The Claria sharesource system has been used for pediatric patients for about 2 years in our country. In this national, multicenter study, we aimed to evaluate the perceptions of patients/caregivers, PD nurses, and physicians about the advantages and disadvantages of CSS by using a network-based questionnaire.

Methods

Three different questionnaires prepared by the researchers via Survey Monkey for the patient/caregivers, PD nurses, and pediatric nephrologists were sent to 15 centers that have been using CSS for more than one year as of the end of 2019. Each center had at least one pediatric nephrologist and only one PD nurse in the setting. Questionnaires consisted of yes/no and multiple-choice questions. The questionnaires were given to caregivers by physicians during their clinical visits. If adolescent patients were able to apply APD themselves, they answered the survey. Before being given the questionnaire, the contents and purpose of the questionnaire were explained in detail to the patients and their parents, and informed consent was obtained. This study was approved by Gazi University Ethical Committee (03.06.2019, No: 41).

Results

The answers of 22 physicians and 15 nurses were evaluated. Almost half of the pediatric nephrology specialists (48%) had 3–10 years of PD experience. Similarly, 53% of the nurses had 3–10 years of pediatric PD nursing experience. Two thirds of PD nurses (67%) and 78% of the physicians reported that they had updated their PD knowledge in congresses and symposia in the last 3 years. Most (91%) of the physicians reported that they had knowledge of the system, and approximately three-fourths of them learned about the system from experts (Baxter representatives) and the remaining from their colleagues and PD nurses (Fig. 1).

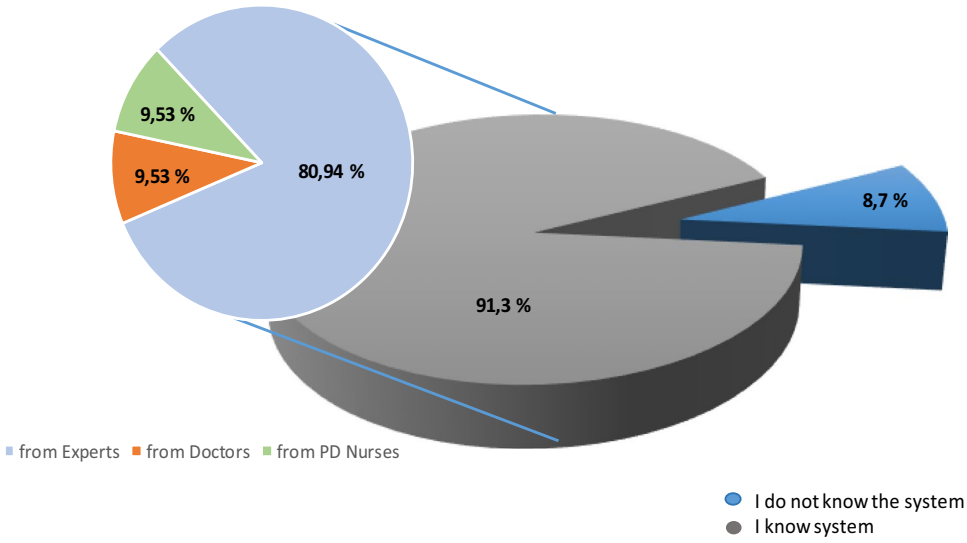

Fig. 1 System recognition among physician

The responses of the physicians and nurses for the CSS are given in Table 1. All physicians and most of the nurses (87%) expressed the same opinion that CSS provides online, objective, and reliable clinical data to detect PD technique-related problems. Similarly, it was the common opinion of both groups that it gives rise to a proactive approach to problems (early intervention). A total of 67% of the physicians and 59% of the nurses reported that problems detected in CSS data were first evaluated by the PD nurse, and the physician was informed if the problem could not be resolved. On the other hand, 73 vs. 41% of the PD nurses and physicians thought that this is a primary nursing tool ($p < 0.05$).

Most physicians (68–100%) reported their positive perception of the significant benefits of CSS (Table 1). Seventy-three percent of them reported that the system has the potential to improve patient monitoring. Two thirds (68%) of the physicians also thought that CSS may help save time for both patients and healthcare professionals by decreasing frequent visits, but does not affect the financial burden of the family and healthcare system (Table 1).

The responses of the nurses regarding the clinical benefits of CSS are given in Tables 1 and 2. Seventy-three percent of nurses suggested that CCS is not well known by physicians and only one-third (33%) reported that physicians use CSS-derived data during their clinical visits. Half of the nurses reported reviewing the data of all patients every morning (Table 2a). Seventy-three percent of the nurses reported that CSS increased patient adherence to PD treatment by enabling shared responsibility and 80% stated that observing non-adherence with treatment (early termination of dialysis,

Table 1 Responses of nurses and physicians regarding the Claria sharesource system

Common relevant responses	Nurse	Physician
CSS is a primary nursing application	73% ($n=11$)	41% ($n=9$)
Problems are detected online by using objective and reliable clinical data	87% ($n=13$)	100% ($n=22$)
Problems can be solved in a proactive manner	80% ($n=12$)	82% ($n=18$)
PD nurses first attempt to solve the problem seen in CSS platform prior to physician involvement	67% ($n=10$)	59% ($n=13$)
CSS improves patient monitoring	87% ($n=13$)	73% ($n=16$)
CSS helps save time for everybody	73% ($n=11$)	68% ($n=15$)

Table 2 Suggested clinical benefits of the Claria sharesource system: PD nurse perspective

a. Nurse perception	
Physicians know less about CSS compared to nurses	73% ($n=11$)
Physicians use CSS-derived data during their clinical visits	33% ($n=5$)
If the physician is more involved/dominant in the system, the benefit will increase	60% ($n=9$)
It should be mandatory to enter BW and BP during connection, to evaluate the volume status better	20% ($n=3$)
Every morning, I review only in patients, new patients, and troubled patients	40% (n=6)
I review all patient data every morning	47% ($n=7$)
b. Clinical benefits of the system observed by nurses	
It increases the adherence of the patient to PD treatment by giving a more equal role to the patient and physician/nurse in responsibility-sharing	73% ($n=11$)
There are no differences in PD treatment adherence between patients switched to CSS and those who started with CSS at the beginning of APD	40% ($n=6$)
Documentation of non-adherence with PD treatment (early termination of dialysis, not waiting for drainage time, by-passes, etc.) forces the patient to perform it as prescribed	80% ($n=12$)
Prolongs the stay of the patient on PD	53% ($n=8$)
Helps reach target BW and effective BP control	60% ($n=9$)
Helps distinguish conditions causing low drainage volume such as constipation and catheter tip migration from UF deficiency	47% ($n=7$)
This system is a good training tool for the patient (fluid balance, dialysis treatment, etc.)	53% ($n=8$)
Adherence to medications related to CKD complications is better in patients on CSS	27% ($n=4$)

not waiting for drainage time, bypasses, etc.) by using CSS data forces patients to perform PD treatment as prescribed (Table 2a, b).

The response rate to the survey among patients/caregivers was 71.4%. Demographic characteristics of 30 patients/caregivers show that about one-fifth (17%) of the patients were under 2 years of age, one-third were in the > 2–5 years of age group, and only 10% were older than 15 years (Table 3). In 80% of the patients, PD was performed by the mothers, and only 7% of the children did self-care. Almost half (47%) of the caregivers were primary school graduates, 10% were illiterate, and only 3% were university graduates. Most of the caregivers were not working in an income-generating job. Almost half of the patients (47%) reported that they reached the hospital in less than 1 h. Most of the patients had been using CSS for more than a year.

The survey responses of patients and caregivers are given in Table 4. Based on patients/caregivers' answers, half of the caregivers (53%) initially thought that they would not learn the system and one-fifth (20%) had a concern that patient care would deteriorate and its quality would decrease. Eighty percent of the caregivers could only talk to the nurses about the system. Almost all of the patients/caregivers (90%) felt safe due to being under constant observation and were happy with no obligation to keep records at home. Half (47%) of the patients had an improved quality of life by applying treatment changes at home directed by CSS data (for example, improvement in edema or dyspnea after changing dialysis prescription).

The frequency of admission to the hospital was reported to decrease in one-fifth (20%) of the patients. Only 3% of patients/caregivers reported reduced time spent in the hospital and saving money. Only 7% of the patients had increased school success and 10% had increased school attendance. With the use of CSS, the sleep quality of 70% of the caregivers improved and the nighttime awakening frequency of patients was significantly decreased (83%).

Discussion

In this study, the advantages and disadvantages of CSS were evaluated at three different levels—patient, physician, and nurse. Most of the participants agreed that CSS improves patient monitoring leading to increased adherence with PD and creating a safe zone for all. Although 53% of patients/caregivers stated that they had initial concerns about their ability to learn CSS, 90% of them reported that they liked being under constant monitoring without any need for their home recordings, which makes them feel safe and comfortable. Two thirds of physicians thought that CSS may help save time for both patients and healthcare professionals by

Table 3 Demographic characteristics of patients/caregivers

Age distribution of PD patients	0–2 years of age	17% ($n=5$)
	> 2–5 years of age	30% ($n=9$)
	> 5–10 years of age	20% ($n=6$)
	> 10–15 years of age	23% ($n=7$)
	> 15–20 years of age	10% ($n=3$)
Primary caregiver	Mother	80% ($n=24$)
	Father	7% ($n=2$)
	Mother-father mutually	7% ($n=2$)
	The patient	7% ($n=2$)
Arrival time to hospital	0.5–1 h	47% ($n=14$)
	> 1–3 h	40% ($n=12$)
	> 3 h	13% ($n=4$)
Educational status of the caregivers	Illiterate	10% ($n=3$)
	Literate	10% ($n=3$)
	Primary school graduate	47% ($n=14$)
	Secondary school graduate	27% ($n=8$)
	High school graduate	3% ($n=1$)
	University graduate	3% ($n=1$)
Does the primer caregiver work in an income-generating job?	Yes	13% ($n=4$)
	No	87% ($n=26$)
How long have you been using CSS?	12 months	83% ($n=25$)
	> 12–18 months	7% ($n=2$)
	> 18 months	10% ($n=3$)

Table 4 Pros and cons of CSS reported by patients/caregivers

Cons		
I initially thought that I could not be able to learn about CSS	53%	($n=16$)
I initially thought that my child's care would be disrupted and the quality of care would decrease	20%	($n=6$)
At first, I was worried that face-to-face visits would decrease	3%	($n=1$)
I always feel like I am being observed	23%	($n=7$)
I can only talk to nurses about the system	80%	($n=24$)
Pros		
I like being under constant monitoring, and it makes me feel safe	90%	($n=27$)
Sharing the responsibility of home treatment decreased my burden	63%	($n=19$)
It is very good that there is no obligation to keep records at home	90%	($n=27$)
Being telephoned is better than having to call the center	47%	($n=14$)
My problems are solved in a much shorter time than before	47%	($n=14$)
Our family adherence to PD treatment increased	63%	($n=19$)
I became more confident in arranging treatment	57%	($n=17$)
Changing therapy according to CSS data improved my quality of life (e.g., I felt safe when edema or shortness of breath was resolved by treatment change)	47%	($n=14$)
My hospital visits decreased	20%	($n=6$)
I have saved my time by eliminating waiting times in hospital	3%	($n=1$)
I have saved money	3%	($n=1$)
The shortness of breath and edema of my child decreased	57%	($n=17$)
My curiosity and responsibility regarding my child's treatment is increased	13%	($n=4$)
The activity and physical capacity of my child increased	3%	($n=1$)
The school success of my child increased	7%	($n=2$)
The school attendance of my child increased	10%	($n=3$)
Compared to the first months, the sleep quality of my child improved, waking up decreased	83%	($n=25$)
My sleep quality improved	70%	($n=21$)

decreasing frequent visits, while only 20% of patients/caregivers agreed with this. Most nurses stated that CSS is a primarily nursing practice platform and if physicians are more involved in the system, the benefits will increase.

The main aim of CSS is to detect and proactively resolve problems online using objective and reliable clinical data, and to provide improved patient monitoring by optimizing patient adherence to treatment. Thus, it can increase patients' adherence to PD prescriptions and may help reduce frequent hospital visits. However, these goals are patient-dependent and there are several barriers to its successful application. As a matter of fact, non-compliance with dialysis prescription is common and associated with increased higher peritonitis rates, decreased technical survival, hospitalization, and mortality [5, 6]. In a systematic review, the rate of non-adherence to PD prescription ranged between 2.6 and 53% [7]. In single-center studies from the USA and multicenter European survey data, it was around 20–40% [5, 8, 9].

Remote management of APD (RM-APD) patients provides more flexible treatment based on the changing needs of patients and can be associated with improved adherence to treatment [10]. Sanabria et al. reported that adherence to PD prescription with the use of RM-APD was more than 90%. In our study, which was conducted before the COVID-19 pandemic, increase in PD treatment adherence was reported by 73% of nurses. Although this rate is highly satisfactory, we expect higher rates of adherence during the course of the COVID-19 pandemic because CSS provides a remote monitoring opportunity to patients which helps reduce the risk of virus transmission by reducing hospital visits. The use of telemedicine reduced the use of emergency departments and hospitalizations, and thus increased parental satisfaction [11]. In line with this, one-fifth of our patients/caregivers reported reduced hospital visits.

In an adult study conducted in Latin America during the COVID-19 pandemic, there was no significant decrease in the rates of peritonitis in patients using RM-APD, but a significant decrease in the proportion of patients with poorly controlled hypertension [10]. This may be partly due to increased self-care of the patients, but mainly due to the positive impact of RM-APD on patient-centered clinical outcomes. It was also shown that the use of RM-APD reduced

hospital visits, improved survival during one-year follow-up, and decreased healthcare costs [12, 13]. In line with this, remotely controlled healthcare systems sometimes reduce time and travel expenses for patients and families and reduce healthcare costs [10]. Recently, Makhija et al. reported that CSS saved time and money [14, 15]. However, in our study, contrary to physicians' expectations, we observed no benefits of CSS on saving time or money, but a slight decrease in hospital visit frequency was reported by parents. In contrast, Marcin et al. reported that providing effective healthcare to pediatric patients who had special needs in a rural setting helped to reduce parental time away from work, reducing travel and affecting the use of emergency services [16].

The duration of the patient's stay in PD is extended with the use of this RM-APD system, and positive clinical results achieved such as reaching the target BW and effective BP control. In a recent study conducted with adult patients, CSS was shown to increase patient adherence to treatment leading to better BP control over time and reducing the daily requirement for antihypertensive medications. In our study, nurses reported their observation that with the use of CSS, it was easier for the patient to reach target BW and effective BP control. In addition, conditions that cause low drainage volume such as constipation and catheter tip migration can be distinguished from UF deficiency, and CSS may be suggested as a valuable educational tool for the patient (regarding fluid balance, dialysis treatment, etc.) [17–22].

A recent study reported that the use of telemedicine reduced school absenteeism and emergency room visits significantly in pediatric patients. Technology also allows pediatric patients to connect with their school during live lessons, and this type of connection is invaluable in terms of the commitment of patients to their peers and maintaining school performance [23]. In our study, a small number of patients (10%) had increased their school attendance. It was also reported that half of our patients took a slightly longer time to reach the hospital, such as 1–3 h or more from rural and nearby areas. Australian registry data showed that 62% of PD patients lived in metropolitan areas, 21% in towns and small cities, and 17% in remote areas. This indicates that about 38% of patients resided in remote areas and had transportation problems to get to health centers [24]. The most important benefit of remote management systems is effective and safe access to professional healthcare services without concern for living in distant areas. This issue is particularly important during the COVID -19 pandemic, due to the fact that public transportation increases viral transmission, particularly in at-risk populations like dialysis patients who have inherent immunosuppression. Especially in the current relatively relaxed regulatory environment, the pandemic presents us with a unique model for testing and increasing the frequency of use of home dialysis delivery and control via remote technology [25].

Sleep pattern is among the basic criteria for quality of life. After switching to or initially starting CSS, our patients and caregivers reported that their sleep quality increased, especially during nighttime. In a recent adult study, the study was standardized according to sleep quality scale before and after CSS use in remote management patients. In the analysis, sleep patterns and patient quality of life were not adversely affected [26]. In this study, sleep quality was increased in most patients and caregivers through use of the system.

High-quality care and high satisfaction rates have been reported by providers, patients, and caregivers for remote management systems [,3, 16, 27–29]. Although the use of CSS seems to have significant advantages, in this study, approximately one-fifth to one-half of the patients/caregivers had anxiety about receiving substandard care while learning the CSS platform. The main reasons underlying the anxiety of using the system were insufficient education (47%), due to the low socioeconomic status and digital literacy of caregivers who graduated from primary and secondary education. With close follow-up by nurses and physicians, early detection and intervention in technical problems may increase patient trust in the system over time. In our study, it was reported that close remote management made most patients feel safe, and in two thirds, the shared responsibility of home treatment decreased patients/caregivers' burdens.

Our limited experience before the pandemic continues to help us identify the barriers to a remote management system. In this study, most of the physicians and PD nurses preferred CSS for pediatric PD patients, regardless of geographical region and distance. On the other hand, after the COVID-19 pandemic, it is expected that telehealth will be used more widely not only for in-home dialysis but also in many other areas including medical education [30].

Conclusion

This survey gives us an initial report about the perceived pros and cons of the RM-APD system from its current users—physicians, nurses, and patients/caregivers. Although it is not a validated survey, prepared by researchers to evaluate the recognition of CSS, a future Delphi survey may provide more reliable and generalizable data. More detailed data on the use of this system and its potential positive impact on patient-centered outcomes should be evaluated through well-designed clinical studies with larger pediatric PD patient groups.

Supplementary Information The online version contains a graphical abstract available at https://doi.org/10.1007/s00467-022-05563-9.

Declarations

Conflict of interest The authors declare no competing interests.

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