



HAL
open science

A feasibility study for understanding the demand and acceptability of a systematic symptom monitoring process in end-stage kidney disease

Laetitia Ricci, Cécile Couchoud, Andreia Carvalho, Marie Buzzi, Francis Guillemin, Carole Ayav

► To cite this version:

Laetitia Ricci, Cécile Couchoud, Andreia Carvalho, Marie Buzzi, Francis Guillemin, et al.. A feasibility study for understanding the demand and acceptability of a systematic symptom monitoring process in end-stage kidney disease. *Journal of Nephrology*, 2024, 37 (9), pp.2687-2689. 10.1007/s40620-024-02153-w . hal-04937538

HAL Id: hal-04937538

<https://hal.univ-lorraine.fr/hal-04937538v1>

Submitted on 10 Feb 2025

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.



Distributed under a Creative Commons Attribution 4.0 International License

A feasibility study for understanding the demand and acceptability of a systematic symptom monitoring process in end-stage kidney disease

Laetitia RICCI*, Ph.D

¹ CHRU-Nancy, Inserm, Université de Lorraine, CIC, Epidémiologie Clinique, F-54000 Nancy, France

² Université de Lorraine, Inserm, INSPIIRE, F-54000, Nancy France
0000-0002-6760-1674

Cécile Couchoud, MD, PhD

³ Réseau Epidémiologie et Information en Néphrologie, REINRegistry, Agence de la biomédecine, Saint Denis La Plaine, France

0000-0002-9273-660X

Andreia Carvalho, MSc

¹ CHRU-Nancy, Inserm, Université de Lorraine, CIC, Epidémiologie Clinique, F-54000 Nancy, France

Marie Buzzi, MD, MSc

¹ CHRU-Nancy, Inserm, Université de Lorraine, CIC, Epidémiologie Clinique, F-54000 Nancy, France

² Université de Lorraine, Inserm, INSPIIRE, F-54000, Nancy France
0000-0003-3002-6976

Francis Guillemin, MD, PhD

¹ CHRU-Nancy, Inserm, Université de Lorraine, CIC, Epidémiologie Clinique, F-54000 Nancy, France

² Université de Lorraine, Inserm, INSPIIRE, F-54000, Nancy France
0000-0002-9860-7024

Carole Ayav, MD, MSc

¹ CHRU-Nancy, Inserm, Université de Lorraine, CIC, Epidémiologie Clinique, F-54000 Nancy, France

0000-0002-0450-7752

On behalf of the REIN Registry

***Corresponding Author**

Laetitia Ricci

CIC-EC

CHRU de NANCY - Hôpitaux de Brabois

Allée du Morvan

54511 Vandœuvre-lès-Nancy Cedex

l.ricci@chru-nancy.fr

Keywords End-stage kidney disease; electronic symptom monitoring; implementation

Patients on dialysis frequently experience severe or overwhelming symptoms that contribute to poor quality of life. Nephrology care teams tend to underestimate the prevalence, severity, and negative effects of symptoms in their patients, while patients often underreport their symptoms. F-SWIFT is the French part of the international project “Symptom monitoring With Feedback Trial” (SWIFT), which was initiated in Australia in 2021. SWIFT aims to assess the extent to which regular electronic symptom monitoring with feedback to patients receiving hemodialysis and their dialysis staff can improve Health-Related Quality of Life at 12 months [1]. To monitor symptoms, the SWIFT project includes the Integrated Palliative Outcome Scale (IPOS-Renal). The IPOS-Renal is a 15-symptom checklist measuring self-reported pain, shortness of breath, weakness, nausea, vomiting, poor appetite, constipation, sore mouth, drowsiness, poor mobility, itching, difficulty sleeping, restless legs, skin changes and diarrhea [2]. The IPOS-Renal takes approximately 9 minutes to complete [3].

The French context seemed to be a priori less favourable than the Australian one regarding the implementation of a Patient-Reported Outcome-based intervention. Indeed, the international project SONG (Standardized Outcomes in Nephrology) had already demonstrated a long-standing interest in involving patients in research in Australia [4]. Likewise, a cross-sectional survey published in 2020 showed that many renal hospitals in Australia and New Zealand collected Patient-Reported Outcomes as part of clinical care [5].

Therefore, to sustain the initial implementation of electronic symptom monitoring in routine nephrology care in the French context, we first needed to explore the perceived benefits and acceptability concerns regarding the F-SWIFT intervention from the perspective of both health care providers (HCPs) and patients.

Epistemological paradigm underlying qualitative methodology is very different from that underlying quantitative methodology. While the main issue in quantitative research is the statistical evidence and its generalization, which depend on an epidemiological design, a qualitative research discusses the notion of transferability. Transferability raises the question of the extent to which results of a study are transferable to other settings. Ensuring trustworthiness in transferability is mainly based on maximal variation sampling strategies for participant selection, maximizing the source variability, and allowing researchers to determine whether the findings might be applicable to similar context. In the framework of the F-SWIFT project willing to evaluate a behavioural intervention in one among multiple countries, consideration for the specific health care system is an essential prerequisite before the launching any implementation process.

A team composed of a nephrologist, an epidemiologist, an engineer in health promotion and a psychologist developed two interview guides, one for HCPs and one for patients that mirrored each other. Three meetings were necessary to establish the guides exploring perceived benefits and acceptability concerns of the F-SWIFT intervention (see Supplementary file S1).

A project manager (Master of Science degree) specialized in health promotion with qualitative research expertise conducted interviews and focus groups in 2 hospital-based dialysis facilities and 1 home or non-hospital based dialysis facilities, in two regions: Eastern France and Southern France.

We included patients with various profiles concerning length of end-stage kidney disease (ESKD), therapeutic modalities and frequency of dialysis per week. Fourteen patients participated in focus groups (see supplementary Table S2 for a complete description of patients' characteristics).

In addition, we conducted focus groups or individual semi-structured interviews with 18 HCPs - 5 nephrologists, 3 head nurses, 3 advanced nurses, 6 nurses and 1 assistant nurse- (see supplementary Table S3).

Focus groups and interviews took place during the COVID-19 pandemic from January to June 2022, and were conducted by videoconference (Microsoft Teams^o). All interviews were integrally audio-recorded and transcribed verbatim i.e. word to word. Therefore, a thematic inductive analysis of these texts was conducted using NVivo v11 to extract the meaning and meaningful statements.

We conducted a thematic inductive analysis using NVivo v11. All interviews were double coded by two researchers, who resolved coding disagreements by discussion. Final intercoder agreement was satisfactory (Cohen's kappa coefficient=0.87). (see supplementary S4 for illustrative quotes of our thematic analysis from HCPs' and patients' perspectives separately). No comparison with the Australian acceptability study was made at this stage, as it was not in the scope of this pre-implementation study in the French context.

Regarding demand (perceived benefits), most patients did not perceived an a priori benefit of the F-SWIFT intervention since they believed that HCPs already monitored their symptoms, either during discussions with the doctor or thanks to nurses' intuitive skills. However, they perceived an interest in the case of a reduced availability of HCPs. The F-SWIFT should therefore include an explanation about the interest of an objective and systematic assessment of symptoms, as compared with simple informal reporting. On the other hand, Table 1 shows that HCPs clearly perceived benefits of a systematic symptom monitoring process (e.g., screening disease beyond the scope of ESKD, reduction of discordant views between HCPs and patients, completeness of the IPOS-Renal, continuous adjustment of actions undertaken to relieve symptoms).

The Australian team that initiated SWIFT also collected the perspectives of patients and HCPs [3] and found SWIFT to be an acceptable intervention. However, Australian HCPs were skeptical that routine electronic symptom collection “*would be effective in the absence of high-quality evidence showing clinical benefits in the ESKD population*”. In France, the culture of scientific evidence is missing among nursing staff in comparison with English-speaking nations such as Australia [6], which might explain why no one among the interviewed nursing staff in our study discussed evidence-based statements for the intervention. For nephrologists, the only perceived barriers were related to logistics (e.g., graduation of alerts, integration of data into the medical file), but the benefit of the intervention, which appeared to be obvious, was not questioned. Therefore, contrary to our initial assumption, the French nephrology context appears to be more favorable for the implementation of the SWIFT than the Australian context, since the intervention seems to meet a strong expectation with no expressed reluctance.

Concerning the acceptability of the intervention, our results underline two major issues (see Table 1). First, the IPOS-Renal results should be integrated directly into patients’ health records and not in another circuit of information. Second, both HCPs and patients reported the need for a prompt and effective reaction from the medical team in case of problematic symptoms to support the sustainability of the intervention and maintain patients’ adherence. Therefore, the F-SWIFT intervention should include a feedback from HCPs to confirm to patients that they have considered the alert. The idea is to avoid discouraging patients who may fear that HCPs will not read the information in their health record. Additionally, feedback to the patient should not be distressing but rather comforting.

This feasibility study based on qualitative research methods, which aimed to understand the demand and acceptability of a systematic symptom monitoring process, allowed us - as

recently recommended by the Medical Research Council [7]- to adapt a complex intervention, initially developed in Australia to the French health care system context. In particular, we showed that tools that fit in the Australian context may need an in-depth adaptation to a different setting.

Moreover, the mobilisation of qualitative methods appeared as a relevant way prior to fit the envisioned intervention to a different national health care system. Consequently, our paper also refers to a general methodological consideration arguing for the use of qualitative methods to optimize initial implementation by adapting the intervention to the national context.

Supplementary Information are available upon request to the corresponding author.

Acknowledgments The authors thank the patients and HCPs who participated in individual interviews or focus groups. Our thanks also go to Amandine Ostermann for her help in the administrative management of the project. The authors acknowledge the work of Emilie Culminique and Sandrine Grandclere for their contribution in the transcription of interviews.

Author contributions All authors contributed to the study conception and design. Material preparation, data collection and analysis were conducted by Laetitia Ricci, Cécile Couchoud, Andreia Carvalho and Carole Ayav. The first draft of the manuscript was written by Laetitia Ricci and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Declarations

Ethical approval The protocol was approved by the Comité de Protection des Personnes (CPP (Est II)) (no. ID- RCB: 2021-A00776-35, CPP no.: 2020IP036).

Informed consent to participate All participants provided written and oral consent.

Competing interests The authors declare that they have no conflict of interest.

Data Availability Statement Full participant transcripts have not been included in the manuscript because of participant confidentiality. Should researchers wish to work on our data, we will proceed with a confidentiality agreement drawn up under the supervision of our local data protection lawyer.

Funding This study was supported by a grant from the Agence de la Biomédecine “Appel d’offre recherche REIN 2020”. The funders played no role in the study design, data collection, analysis, reporting, or the decision to submit for publication.

The sponsor was CHRU de Nancy (Direction de la Recherche et de l’Innovation).

References

1. Greenham L, Bennett PN, Dansie K, et al (2022) The Symptom Monitoring with Feedback Trial (SWIFT): protocol for a registry-based cluster randomised controlled trial in haemodialysis. *Trials* 23:419. <https://doi.org/10.1186/s13063-022-06355-0>
2. Raj R, Ahuja K, Frandsen M, et al (2018) Validation of the IPOS-Renal Symptom Survey in Advanced Kidney Disease: A Cross-sectional Study. *J Pain Symptom Manage* 56:281–287. <https://doi.org/10.1016/j.jpainsymman.2018.04.006>
3. Viecelli AK, Duncanson E, Bennett PN, et al (2022) Perspectives of Patients, Nurses, and Nephrologists About Electronic Symptom Monitoring With Feedback in Hemodialysis Care. *American Journal of Kidney Diseases* 80:215-226.e1. <https://doi.org/10.1053/j.ajkd.2021.12.007>
4. Tong A, Manns B, Wang AYM, et al (2018) Implementing core outcomes in kidney disease: report of the Standardized Outcomes in Nephrology (SONG) implementation workshop. *Kidney Int* 94:1053–1068. <https://doi.org/10.1016/j.kint.2018.08.018>
5. Morton RL, Lioufas N, Dansie K, et al (2020) Use of patient-reported outcome measures and patient-reported experience measures in renal units in Australia and New Zealand: A cross-sectional survey study. *Nephrology (Carlton)* 25:14–21. <https://doi.org/10.1111/nep.13577>
6. Ricci L, Beguinet M, Guillemin F, Klein S (2021) French nurses' and allied health professionals' perception of research in their fields: A descriptive qualitative study. *Int Nurs Rev*. <https://doi.org/10.1111/inr.12709>
7. Skivington K, Matthews L, Simpson SA, et al (2021) A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ* 374:n2061. <https://doi.org/10.1136/bmj.n2061>

