Offering Patients Therapy Options in Unplanned Start: Development and Implementation of an Education Program for Unplanned-Start Patients

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Unplanned start of dialysis is still a common and important problem for dialysis units in Europe and across the world: 30%–50% of patients can commence therapy in that way. Such patients are known to experience increased morbidity and mortality, to make greater demands on health care resources, and to be less likely to receive their dialysis modality choice. We therefore aimed to meet the specific needs of unplanned-start patients by developing and implementing an Unplanned Start Educational Programme in dialysis units.

The new program—which is intended to effectively influence the clinical pathway for patients and to equip health care professionals with the tools necessary to support and optimize the process of unplanned dialysis start—was created with the support of 5 dialysis units and academic experts in patient education. It involves process mapping of patient flows so as to recognize the key steps in the management of unplanned dialysis. Following its successful development, the Unplanned Start Educational Programme was delivered to patients.

To evaluate the effectiveness of the program, an observational study, Offering Patients Therapy Options in Unplanned Start, had the primary outcome of measuring the impact of the education program on dialysis modality choice (peritoneal dialysis or hemodialysis).

Key words
Unplanned start, acute dialysis, education

Introduction

This paper describes the development and implementation of an education program to support patients starting dialysis in unplanned way to make informed modality choices. In addition, the program can assist health care professionals to change and optimize the clinical pathway such patients take.

In the literature, the definition of unplanned dialysis varies and can depend on

- use of a temporary access (central venous catheter) at the first dialysis session; and
- time of referral to the nephrology unit (early vs. late), describing those who are known (early referral) or unknown (late referral); or
- the starting creatinine level and estimated glomerular filtration rate; and also
- the timing of the need for dialysis (contrasting emergency dialysis within, for instance, 48 hours with urgent dialysis within 1 – 4 weeks).

The overall unplanned dialysis population is therefore composed of patients either known or unknown to the nephrology unit, who start dialysis in an urgent or emergency manner with a temporary vascular access. The prevalence of unplanned dialysis is estimated at 30% (1); however, a review by Mendelssohn *et al.* (2) demonstrated that the percentage of unplanned dialysis often exceeds that percentage, fluctuating around 40%

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and showing that unplanned dialysis is still a common problem in dialysis units across the world.

The consequences of unplanned dialysis start are well described in the literature. First, compared with planned-start patients, unplanned-start patients who lack a mature dialysis access experience a mortality risk within first 90 days that is increased by a factor of 3.6 (3). Second, unplanned-start patients make a greater demand on health care resources, including hospitalization at initiation and during first 6 months of dialysis (4). Moreover, most unplanned patients receive in-center hemodialysis (HD) with a temporary catheter access as the default dialysis option, and most will never be given the choice of home therapy (5). In addition, patients who start on HD with a central venous catheter are at high risk for prolonged use of the catheter and for the associated increased occurrence of further complications (6). Finally, compared with peritoneal dialysis (PD) or with HD by arteriovenous graft or fistula, use of a central venous catheter at the start of dialysis is associated with a significantly increased mortality risk (7).

Early referral to a nephrologist is associated with reduced mortality and hospitalization, better uptake of PD, and better dialysis preparation, including timely placement of a dialysis access (8). Early referral is one option to reduce the impact of unplanned dialysis start, but it can be difficult to achieve in many hospitals and health care systems. However, if the referral pathway cannot be changed, and if unplanned starts cannot be prevented, patients could enter an education program that allows for modality choice. In planned-start patients, education programs significantly affect the distribution of dialysis modalities, increasing the proportion of patients on PD and optimizing the predialysis management process (9,10). In addition, there are data to show that unplanned patients can be started on PD, achieving outcomes that are the same or better than those achieved with unplanned HD (11). Moreover, according to the most recent U.S. data, an unplanned PD start can also be more cost-effective than an unplanned HD or dual-modality (HD and then PD) start (12).

It should therefore be possible to design and implement an education program for patients making an unplanned dialysis start, as well as an optimized health care process to deliver informed decision-making and use of home dialysis. Such a program could then be implemented in many renal units across various health care systems.

Methods

The Unplanned Start Educational Programme was developed in an attempt to modulate the management of unplanned-start patients. It consists of an education program, together with an examination and optimization of the flow of unplanned-start patients within a specific renal unit. The education program was developed with the support of 5 dialysis units in Europe and advice and input from academic experts in patient education. The program focuses on the key decision that the patient must make: which chronic dialysis modality to pursue (including the further procedures to create an arteriovenous fistula or to insert a PD catheter). That decision is emphasized throughout the educational material, which covers HD, PD, home HD, and conservative care.

During at least 3 individual sessions, a motivational interviewing methodology is used to deliver the Unplanned Start Educational Programme to patients at a pace determined by the educating nurse, who assesses the clinical condition and response of the patient. Supporting materials—including a patient booklet matching the educational material delivered by the nurse and a unit-specific video or DVDs—are also available.

A literature search demonstrated the additional potential benefits of using decision-support tools in the modality selection decision (13). Decisions aids are support tools that present a detailed, specific, and personalized picture of options and outcomes to prepare people for decision-making. They differ from health education materials, which tend to be broader in perspective (helping people to understand diagnosis, treatment, and management, but not assisting with a specific personal choice between options). A systematic review of the use of decision aids demonstrated that such aids can improve knowledge, make expectations more realistic, enhance active participation, and decrease the number of people remaining undecided.

Decision aids for use during the discussion with the nurse educator were developed for the unplanned-start patients. The aids included the generic Ottawa online decision aid, a balance scale, and decision support cards prioritizing the value of specific issues and factors related to dialysis modalities. Depending on the clinical condition of the unplanned patient at referral time, that patient presenting to a participating nephrology unit could be directed into the Unplanned Start Educational pathway, with its 3 key steps: referral

of all patients by inpatient or outpatient renal unit staff to an education program conducted by an identified educator, decision-making about a dialysis modality after education with the assistance of decision-support tools, and finally processes to ensure timely placement of a permanent dialysis access.

The Unplanned Start Educational Programme also includes tools to examine patient flow and the hospital processes used to manage unplanned-start dialysis patients. These specific approaches were used:

- Analysis of the flow of all incident patients to the renal unit, split into planned and unplanned dialysis start, and including the first dialysis modality, with subsequent therapy switches over a 12-month period.
- Process mapping, by the multidisciplinary team, of the pathway from referral to placement of a permanent access for unplanned-start patients in the individual units. Process mapping is widely used in health care improvement approaches to help understand complex and fragmented health care systems and processes. The members of the multidisciplinary team work together to identify each step in the process used to manage unplanned-start patients so as to identify opportunities for improvement and to generate ideas for testing improvements.

Results

The Unplanned Start Educational Programme was successfully developed and made available for implementation in renal units. Renal units identified key members of the multidisciplinary team to implement the program within their dialysis unit. Key individuals received training in the use of the patient education program, including the theory and practice aspects of motivational interviewing techniques.

The renal units then performed a baseline patient flow analysis examining the flow of all incident dialysis patients in the preceding 12 months. The analysis facilitated an understanding of the size of the unplanned-start patient problem within the particular dialysis unit. The units then performed process mapping to carefully evaluate their particular unplanned-start patient pathway, identified key challenges, and made changes to improve the management of the unplanned-start patients, identifying how and when education would be delivered and understanding the issues relating to permanent access placement.

An observational study was designed to evaluate the effectiveness of the Unplanned Start Educational Programme with respect to the dialysis modality choice made by unplanned-start patients and the clinical outcomes in unplanned start. The OPTiONS (Offering Patient Therapy Options in Unplanned Start) study was a non-interventional prospective study conducted in 26 centers in 6 European countries. All unplanned-start patients who met the inclusion criteria (being referred to the nephrologist within 1 month of needing dialysis, or being followed by a nephrologist but needing urgent dialysis with a central venous catheter) were eligible and were followed for 12 months. The primary outcome is the impact of the Unplanned Start Educational Programme on dialysis modality choice (PD or HD). The main data collected during the study included the baseline demographics of the unplanned-start patients, their medical history, a description of the referral source (type and time), estimated glomerular filtration rate at referral and at the time of first dialysis session, primary dialysis modality and subsequent changes, survival, number and length of hospitalizations, access type and access-related procedures, and occurrence of related infections.

The implementation of the Unplanned Start Educational Programme is being assessed to understand how many unplanned-start patients received the education package and when in the course of their clinical presentation they received it. The number of patients completing the program and the number making a modality decision were measured, together with the nature of the final modality chosen: PD, HD, or home HD. During the follow-up phase of the study, the number of patients actually commencing their chosen modality was recorded, together with their clinical outcomes.

Recruitment and 12-month follow are now complete, and a detailed analysis of the results is taking place. Table I shows important baseline demographics of the unplanned-start patients, including age, preponderance of men, and significant comorbidity. Table II shows the characteristics of all incident renal replacement therapy (including planned and unplanned) patients in participating countries (14) as a comparator.

Discussion

The Unplanned Start Educational Programme was developed to address the specific needs of patients starting dialysis in an unplanned way. It is important

TABLE I Baseline characteristic of patients in the OPTiONS study

Characteristic	*Value*
Patients (*n*)	270
Mean age (years)	65.1±16.4
Race (%)	
Asian	1.5
Black	0.7
White	91.1
Missing/unknown	6.7
Sex (% men/women)	64.4/35.6
Comorbidities (%)	
Diabetes	41.5
Congestive heart failure	30.7
Myocardial infarction	18.2
Peripheral vascular disease	17.8
Mean CCI score	6.4±2.7
Primary renal disease[a] (%)	
Chronic renal failure, cause unknown	12.6
Glomerulonephritis	20.0
Renal vascular disease	20.0
Diabetic nephropathy	25.2
Other[b]	22.2
Mean eGFR, first dialysis session	8.4±5.3

[a] Grouping applied.
[b] Pyelonephritis, interstitial nephropathy, cystic kidney disease, inherited renal disease, renal hypoplasia, multisystem renal disease, myeloma, amyloid, other renal disease.
CCI = Charlson comorbidity index; eGFR = estimated glomerular filtration rate.

TABLE II Characteristics of incident renal replacement therapy patients in participating countries[a]

	Patient variables		
Country	*Mean age (years)*	*Sex (% men/women)*	*Diabetes (%)*
Austria	64.8±15.3	68.3/31.7	25.9
Denmark	64.1±16.7	65.4/34.6	27.8
France	67.1±16.3	63.6/36.4	21.5
Sweden	63.4±17.6	65.2/34.8	22.7
United Kingdom	62.2±15.6	62.0/38.0	23.7
Germany	No data reported to ERA-EDTA		

[a] From European Renal Association–European Dialysis and Transplant Association (ERA-EDTA) Registry, 2012 (14).

to consider initiatives to improve clinical outcomes and to allow for greater patient autonomy through informed decision-making. The existing literature shows the positive impact of patient education programs on the choice for home therapy (9,10,15), but also the feasibility and challenge of delivering such education, given conditions of restricted time and clinical concerns related to urgent dialysis start.

Here, we described the development process for the Unplanned Start Educational Programme, in which patient education focuses on modality decision rather than on the wider issues relating to chronic kidney disease and its complications. The latter information is very important for patients, but can be delivered at a later time, after the unplanned start. Decision support tools were developed to be used with the patient as part of the decision-making process. Subsequently, other groups have developed decision aids for patients making decisions about dialysis modality (16), and those aids are now being used in clinical practice, although not specifically with unplanned-start dialysis patients. Other studies will confirm their benefit in assisting dialysis modality decision-making and whether changes in the use of home dialysis result. A recent consensus review of dialysis modality education (17) recommended the use of patient decision aids by the multidisciplinary team who are counselling and informing the patient.

The other key element of the Unplanned Start Educational Programme involves ensuring that the dialysis unit understands the patient pathway from presentation to formation of a permanent dialysis access—not only in terms of patient numbers, but also in terms of detailed process mapping steps. Understanding the pathway is vital to be able to streamline processes and determine in detail the timing of education, the resource requirements, and the organization of dialysis access (18). That information assists the multidisciplinary team in planning for education within their own service based on the available resources (19).

The effectiveness of the Unplanned Start Educational Programme has been examined during the OPTiONS study performed in several European countries; results will be published in 2015. Baseline demographics presented here demonstrate that unplanned-start patients present challenges relating to age and comorbidity. However, the demographics of unplanned-start patients are otherwise similar to the overall incident dialysis population in the same

countries [Table II (14)]. The results of the OPTiONS study will demonstrate the feasibility of delivering patient modality choice to unplanned-start patients and the clinical outcomes that ensue. This group of patients experience several clinical disadvantages that affect outcomes, and any intervention that proves beneficial for clinical or patient-reported outcomes would be of interest to all renal units.

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