

Patient-centred initiatives in the dialysis unit

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■ WHERE ARE WE NOW?

Dialysis treatment for chronic kidney disease (CKD) has been at the forefront worldwide of improvements in the delivery of healthcare for chronic diseases and innovation in models of care and reimbursement for that service. No other field of medicine has received the same scrutiny from health authorities and has such a wealth of data gathered on its structure, process and outcomes of care to demonstrate its success.

In 2008, our end-stage renal failure programme became the first disease state to have a prospective bundled payment system (the so-called “comprehensive price”)¹. As part of our reimbursement agreement, the payer (health authorities) required the demonstration of achievement of certain quality targets in predefined key performance indicators (KPI), as a tool to monitor the quality of care delivered in our dialysis units.

Those were not good quality indicators; they were never submitted to discussion or validation by stakeholders and they are now extremely outdated. However, they quickly came to embody the entire quality of care narrative. Like others worldwide, we embraced this new target culture, one which translated into a lot of energy being diverted into responding to quality measurements. The danger is that health authorities, patients and even physicians may begin to identify high quality simply as high scores on quality indicator measurements. New generations of physicians will be paid on that basis; thus they might not even

understand that most aspects of the quality of medical care are not measured.

Unfortunately, most established Key Performance Indicators (KPIs) are not supported by robust scientific evidence (haemoglobin, ferritin, or phosphate targets). Undue focus on certain KPIs can lead to potential adverse effects (strict dry weight prescription, IV iron prescription to achieve supernormal ferritin levels). Other KPIs cannot be improved either because their score was already optimized (Kt/V), or because no matter what we do, the indicator only fluctuates month after month without any substantial improvement (over hydration). On the other hand, some KPIs are not influenced by health professional interventions (mortality, albumin); therefore they cannot be a measure of performance and, above all, most of them do not contribute to change hard outcomes, or are not sensed by patients as boosting their health related quality of life (HRQOL).

What we measure usually improves, but what we measure may have only a vague association with the outcome we are looking for. Improved process quite often does not translate into improved outcomes; therefore our quality targets must be selected based on their true clinical relevance.

Rewarding the achievement of a process indicator (Hb, Phosphate, Kt/V and so on) is fair, as medical decisions have a more direct impact on process than on outcomes, but may result in a system which rewards compliance rather than performance, and physicians will be consumed in meeting laboratory

quality metrics, losing sight of the patient as a whole².

There is a tendency to confuse what is important for the patient with facility-level based metrics. A key driver for prioritization of any KPI is that it has a large impact on a desirable hard outcome, either a measure of effectiveness (mortality, hospitalization, patient experience of care) or, what matters most, health-related quality of life³.

The U.S. National Quality Forum recently provided rigorous criteria for choosing facility-level (not to be confused with patient-level) indicators. A key criterion for the development of a KPI is importance defined as the extent to which the proposed measure focus is evidenced-based, important to making significant gains in healthcare quality, and improving health outcomes for a high-impact aspect of healthcare where there is variation in or overall less-than-optimal performance³.

Operating in this system on a daily basis and being in charge of monitoring the performance of all units in our network, I became concerned with the fact that in quite a few KPIs in the same unit and despite the effort of the clinical staff, we do not record any major or consistent improvement month after month, just meaningless fluctuations. Also puzzling is the fact that, most commonly, those units which perform better in certain KPIs do not have better hard outcomes (hospitalization rate or mortality). We should be able to understand why in different units, performance differs despite similar comorbidity indexes and identical medical practices, but we don't. Once you have a certain amount of patients on target for your KPI, whenever you try to improve at one end of the target interval, things get worse at the other end. It is just the way it is.

What should we do? Drop those KPIs? Launch a broad, fast, register-based study to find out inside the organization if it makes sense, for outcome sake, to insist on that KPI? Make that KPI a priority and completely overhaul the whole structure of care to achieve a better score, even if that means less and less true (classic, individualized) medical care and more assembly line medicine (protocol-driven medicine)? Or just conclude that the whole system, although conceptually interesting, is not providing meaningful answers.

The most common argument in favour of prioritizing action over evidence is that the need to address quality and safety problems is urgent; however most quality-improvement interventions involve changes in the organization of complex systems, and the law of unintended consequences tend to apply to such interventions. Common excuses are the effectiveness of some quality-improvement strategies is obvious, or the framework of evidence-based medicine does not apply to quality improvement⁴.

However, given the impact of KPIs on physician behaviour and priorities, it is not wise to compromise on the evidence behind an indicator simply for the sake of measuring something, anything.

In summary, we shall not become a hostage to KPIs (which were hardly validated), or guidelines (essentially eminence-based), and never assume that looking at an Excel file in our office means we can dictate patient care or predict outcomes. Biology will always fool us.

■ A NEW PARADIGM

Dialysis facilities accumulate large amounts of data to demonstrate compliance with arbitrary standards of care, but where does that leave the individual patient and the nephrologist trying to understand how best to provide care for each patient?

Our ultimate goal should be to maximize a patient's perception of his quality of life, not forgetting that there are fundamentals of care (haemoglobin, Kt/V, vascular access, among others) which still are the building blocks for achieving that target.

There is ample evidence that performance measurement and performance incentives improve the quality of documentation and the achievement of certain easily measurable clinical targets, while having a much more limited effect on underlying standards of care⁵.

In this context, along came the concept of "Patient-Centred Care", which made it to centre stage in the discussion of quality, enshrined by the Institute of Medicine's "Quality Chasm Report" as 1 of 6 elements of high-quality care.

Patient-centred medicine seeks to focus medical attention on the individual patient's needs and concerns⁶. Nelson and co-workers illustrated the value of systematically collecting information on patients' concerns and priorities at the point of care and using outcome measures which they identify as valuable⁷.

We need a better understanding of what people need from health and social services, and to include patients and caregivers in our multidisciplinary teams of providers⁸. To do that we need appropriate training on patient interviewing, communication of sensitive information, identification of patients' priorities and preferences, as well as time to do it and the capability to translate what we learned from them into an individualized and effective care plan.

Dialysis population is heterogeneous. For those patients of limited life-expectancy as the result of advanced age or severe comorbidities and for whom dialysis will be the final treatment destination, their complex medical and social situation fits poorly into the homogeneous, disease-centred and process-driven approach of many clinical practice guidelines which impose a treatment burden not translated into a proportional improvement in HRQOL. A patient-centred approach respects patients' preferences and goals of care, emphasizing palliative management strategies⁹.

Does the frail and emaciated 80-year-old patient with ischaemic heart disease, a faithful representative of many of our patients, really need to comply with 12 weekly hours of treatment, 70 litres of substitution fluid, a Kt/V above 1.4, or even to be dialyzed through a native AV fistula? Maybe these are not his top priorities.

In the U.S., the Centers for Medicare and Medicaid Services (CMS) implemented the ESRD quality incentive programme in which dialysis providers are paid for performance on predefined quality measures. This programme was criticized because these measures were largely disease-oriented and did not reflect outcomes aligned with patients' values, needs and preferences. They are now recommending to dialysis units a transition to broad-based, patient-centred assessment of care.

Suggested new indicators include: a) Available high quality palliative care (symptoms control, intervention

in depression and psychosocial stressors); b) Kidney disease HRQOL; c) Issue of an advance care plan/advance directives; d) Symptoms control (pain, itching, nausea, poor energy and so on); e) Care coordination, difficult to achieve in our system of senseless shared responsibility with primary care; f) Prevention of hospitalization risk; g) Medication reconciliation. The list goes on¹⁰⁻¹³.

■ PROBLEMS AND CAVEATS

Patient-centred medicine is above all a metaphor. Patient-centred is commonly used by contrast with doctor-centred, replacing a Ptolemaic universe revolving around the physician with a Copernican galaxy revolving around the patient. The flaw in the metaphor is that patient and doctor must coexist in a therapeutic, social and economic relation of mutual prerogatives. Neither is the king and neither is the sun. Health relies on collaboration between the patient and the doctor, with many other people serving as interested third parties. Therefore, patient and doctor must meet as equals⁶. In my view the concept of patient-centred is indeed opposed to disease-centred, or even guideline-centred, but not to doctor-centred.

There are concerns that patient-centred care, with its focus on individual needs to be addressed on their terms, might be at odds with an evidence-based approach, which tends to focus on populations. The debate can be laid to rest if we all agree that a good outcome must be defined in terms of what is meaningful and valuable to the individual patient¹⁴.

Many measurements which assess patient-centred medicine confound behaviours with outcomes, leading to confusing results. Patients may be satisfied with their physician's listening skills; they may feel respected, engaged and knowledgeable, and still their chronic disease control may worsen. We have to understand the pathways through which patient-centred care behaviours contribute to better outcomes¹⁴. We are certainly lagging behind on this translation from understanding the problem to effectively responding and solving it.

Among several limitations lies the fact that an individual's perception of his quality of life fluctuates over time depending on a variety of health, family, financial

and personal circumstances. Mor *et al.*, for instance, observed that although the vast majority of women treated by chronic haemodialysis rarely have sexual intercourse, only 10% of those women identified this issue as an area of concern¹⁵.

No matter how much patient knowledge we provide, we can never be sure that their preferences and decisions today are in their best interest in the mid- and long-term. We need to consider how the information obtained from questionnaires translates into improving patient's health experience and adjustments to the realities of end-stage renal failure, or how the dialysis staff can affect individual patient's problems¹⁶. How do we measure and monitor patient-centred care and interactions? We cannot simply enter a number as we do in Kt/V. It involves a process incorporating a team open to dialogue and feedback. The focus of nephrologists', nurses', social workers' and dietitians' interactions will change to patient education, shared decision-making, and exploration of patient's concerns¹². The regulatory environment will have to change to support a patient-centred care approach.

■ PLANNING AND IMPLEMENTATION

If we want to proceed to this next level, I would recommend:

1. Educating our staff to be ready for this new paradigm. Palliative Care specialists can help us to develop our new skills.
2. Still maintaining the old, disease-centred performance indicators, and being prepared to deal with conflicts with patients who, given the chance to express their preferences and expectations, may choose to drop care goals such as dialysis time, extra-corporeal blood flow, strict diet. We will open a Pandora's box before we are able to fully educate our patients on the rationale of our targets.
3. Adding on new KPIs: a) Health Related Quality of Life (HRQOL), is a must; choose your preferred assessment tool (check the EQ-5D-5L or the KDQOL-SF 1.3 questionnaires). For the time being,

as a quality performance measure, we may only require the demonstration of its use, with a score entered in the clinic database. In the future we can create some kind of Standard HRQOL Rate, a ratio between the average score of all patients in a certain dialysis unit over the average of all scores in the network; b) As a reminder and surrogate for quality of palliative care we may elect pain control, using a "0-10 Numeric Pain Rating Scale"; c) Another item that we desperately need to address is Advanced Care Planning. It is my experience that it is hard to obtain a consensus among our peers; the goal would be to document that patients and their next of kin received information and had a thorough discussion with their nephrologists, giving them the opportunity to decide if they even wanted to discuss advanced care planning; to receive regular and objective information on their prognosis; to be helped in issuing a Living Will and/or to participate with the team in shared decision-making. It is certainly a difficult KPI to implement, but unquestionably the most relevant of them all.

4. Have a monitoring system in place to follow-up closely on hard outcomes (mortality, morbidity, costs, etcetera) and early detection of unintended consequences.

Disclosure: The author works as Country Medical Director for Nephro-Care Portugal and he is in part responsible for our love affair with old-fashioned disease-centred indicators

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