Development of a tool of ePROMs as the main concept of outcome measure in value based healthcare in Luz Saúde - Portugal

Costa F.1, Pinto D.1, Freitas C.2, Castanhera A.4, Fidalgo C.1, Mota F.1, Sousa J.1, Rocha-Gonçalves F.1, Maio R.1

1. Luz Saúde – Value Based Health Care Project 2 - Luz Saúde – IT Department

INTRODUCTION

Luz Saúde implemented an ePROMS platform, aiming at collecting generic and condition specific PROMs, by electronic means, from every secondary care patient at the hospital group. ePROMS at Luz Saúde are a means to measure the outcomes of clinical of treatments and services integrated in the concept of Value based healthcare (VBHC). This application reports on the experience of having developed such platform, that is suitable for large-scale data collection, storage, and analysis and reporting. We also identify the problems encountered and solutions implemented using a generic PROM survey as an example.

As a background, the importance of truly listening to the voice of patients is growing, as health systems strive to position patients at the center of care. Among the key solutions for a more patient-centered clinical practice are the electronic patient-reported outcome measures: ePROMS. These digitally implemented platforms, gifted with validated questionnaires, reveal patients’ views on how health care interventions impact their quality of life. Using patient-reported outcome measures has particular advantages: Patient experience, substantial, physical and psychosocial consequences of the disease and its treatment, and much of the symptom burden occurs outside the hospital. Research suggests, however, that these consequences may be under-recognized and under-treated, for example, in the oncology practice. Recent studies have shown that routine collection of PROMs as part of cancer therapy and follow-up may positively impact the survival and quality of life of cancer patients. In this application, we summarize the benefits of collecting and using PROMs in routine care and follow-up, relying on scientific literature.

RESULTS

Despite the implementation challenges, the potential of ePROMS in improving care is significant and PRO data utilization continues to become increasingly common. The more widespread awareness of the opportunity from applying PROMs we accumulate, the better protocols and ePROM tools we can design. Most importantly, the insight provided by ePROMS helped professionals focus on what matters to patients, provide better and more personalized care – and ultimately, make more of a difference to patients’ health status and quality of life. Nevertheless, we found that the uptake of an ePROM system faces implementation barriers, such as planning and designing the system infrastructure, training users, and engaging staff. Clinicians are often reluctant to use PROMS routinely because they fear it will add to their workload and disturb their workflows rather than make them more efficient and effective.

The quality of data collection must therefore ensure that patients complete their questionnaire unobserved and unaided by care providers. The evidence in favor of self-reporting by patients was robust. From the point of view of the patient, PROMs shift part of the clinical care focus and place them more at the center of care. Being heard in this way had an empowering and engaging effect. The use of PROMs as part of routine clinical care:

- increased patient satisfaction with care: 30%
- improved patient-provider communication: yes as peer interview
- improved overall quality of life: measurement in 10opathologies in more than 100 patients for the pilot
- improved symptom management: measurement in 10 pathologies and active involved with the pathology physicians
- leaded to less frequent hospitalization and admission to the ER: in COPD around less than 40%
- increased to a better survival rates for cancer patients: to be confirmed in a long term study, 5 years or more (replicated Ethan Bash 2017 study)

Perhaps most importantly, PROMs enhanced communication between patients and care providers and improved patient involvement in care planning and decision making. PROMs provided an opportunity for patients to provide input from their perspective and to be more aware of expected outcomes and how they compare.

CONCLUSIONS

For health care professionals, the key benefit of using ePROMS is gaining a better, more systematic understanding of the patient’s outcomes. ePROM data can help the clinician to focus on symptoms that need attention and quickly determine whether symptoms are worsening or improving over time. This insight can be used to modify the care path for the patient and to improve or maintain a high level of care and expected outcomes.

We have collected evidence that the regular use of PROMs facilitates and improves communication between patients and health care professionals: preparatory meeting with patient association, to prepare a national panel to listening to patients, increases awareness of patients’ functioning and wellbeing. Reported high levels of satisfaction from the clinical staff, facilitates shared medical decision-making as patient participation is enhanced. The value and benefits of shared decision making in collaboration with Nova School health & economics Knowledge center at NOVA SBE. Furthermore, alert systems enable clinicians to recognize occurring symptoms in real time despite the geographically distant between the patient and medical services. Because patients track their outcomes between clinic visits and can communicate electronically when there is a change, the timing of appointments and their duration and content can be preplanned by staff, guided by patients’ needs and priorities.

Using electronic systems to track patient feedback requires a certain mindset and a certain level of IT skills from all users: clinicians, staff, and patients.

“...if an egg is broken by outside force, life ends. If broken by inside force, life begins. Great things always begin from inside.” - Jim Kwik

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