PCCNET
International Network for Patient-Centered Care

Newsletter

May 2023

Dear PCC NET members and interested individuals,

In this newsletter, we will provide you with interesting details on how patient-centered care and shared decision-making are promoted at a large cancer center in Santiago de Chile. Also, two papers are advertised in the recent publications section and our next online event is coming up, so save the date!

Kind regards,

Nadine Lages (on behalf of the PCC NET core team)

Interview with Dr. Ricardo Morales on promoting patient-centered care

Thank you very much for sharing your insights with us. First of all, please introduce yourself.

I am the medical director of the Instituto Oncológico Fundación Arturo López Pérez since April 2021. However, I have been working at the institution for six years as a physician and infectologist, particularly in infectious disease care. I am an internist and infectologist, with a master's degree in clinical management and hospital epidemiology and infection control, as well as training in healthcare bioethics, research bioethics and quality of care.

What motivated you to promote person-centered care in cancer care?

In terms of institutional policy, about 4 years ago, we met the Organisation of European Cancer Institutes (OECI), who have a 9-chapter manual that guides us and within those chapters, one area that we had less developed is patient empowerment. Therefore, we are in a process of continuous improvement, to establish improvements in the standards that we partially meet. In this sense, our main institutional focus is to be able to capture the preferences and individual experiences of the cancer patient, respecting the patient's values in relation to those preferences and values, both for them and for their families and caregivers.

That is the main motivation for me in the institution, together with the challenge set by this European organization, which has been a tremendous driver to develop it.

An example of this is that, we started a process to learn about the patient experience through the application of PREMs and PROMs. For example, last year, the breast cancer team presented at a conference in Boston reporting results in breast cancer patients who had undergone surgery. However, one of the challenges going forward is to prioritize these measurements in different areas, not only in breast cancer. We need to deepen and mature it further, hopefully this year, and have more relevant data in different areas on patient satisfaction.

What progress has been made towards person-centered care and shared decision-making at the institutional level? What has facilitated and hindered this progress?

We have had progress such as, for example, the measurements I mentioned, which is a concrete and real progress. It has been very important to know the experience of patients. In fact, we presented it at a clinical meeting for the institution, to disseminate and integrate the concept in the FALP community. Therefore, one of the objectives is to deepen this measurement and extend it to other areas.

Another challenge is financial toxicity, which is a very important issue for us as an institution. I recently read in an article that there are tools such as screening surveys for financial toxicity, considering that cancer is the most economically catastrophic disease that can happen to people.

On the other hand, another aspect where we have made very good progress is clinical trajectories. That is, that a patient is admitted with a diagnosis, regardless of who he or she is seen by, follows a journey in the institution that is defined in the best clinical evidence, which has been adapted to our clinical practice. In that sense, what we managed to adapt that first quarter is the measurement of adherence to those clinical trajectories and we have an improvement strategy that we are going to review in August of this year. This contributes a lot to the patient experience and patient empowerment in decision-making.

What are the next steps and priorities for your management in this area?

Firstly, to deepen and broaden PREMs and PROMs. On the other hand, to establish a cycle of continuous improvement in our clinical trajectories, assessing the points where our adherence may be lower at different milestones. Also consider latency, which is very important for patients and their families, i.e. how long it takes me at each step since I have a diagnosis or the steps I had to go through to get to a diagnosis. This is also measured and these are outcomes that we are always very sensitive to. Finally, I think financial toxicity is an extremely important aspect, for which we need to validate surveys for that purpose.

Recent publications

Risk communication during a health crisis	What is needed to effectively communicate risk during a health crisis? This qualitative study with international experts identified three main best practices. https://bmjopen.bmj.com/content/13/5/e067531.info
Long-term results of Share-to-Care	The Share-to-Care program implements shared decision-making at large scale. Months after initial implementation, patients reported increased shared decision-making. https://doi.org/10.3389/fneur.2022.1037447

Short notes

Save the date!	Prof. Angelique Timmerman will present a new shared decision-making training concept for primary care. When? **12th of July at 16:00 - 17:30 (Germany) / 10 am - 11:30 am (Chile)** Simultaneous translation to Spanish will be provided. More info soon!

We thank Dr. Ricardo Morales for his contribution to this newsletter!

Kind regards,
Dr. Nadine Lages, Prof. Dr. Paulina Bravo, Ivo Engert, Prof. Dr. Dr. Martin Härter, Constanza Quezada, Prof. Dr. Isabelle Scholl