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Towards building capacity in patients and empowering patient voices in Egypt

The turn of the 21st century marked a new era where patient safety was recognised as a prime priority. In a globally expanding world, healthcare has increased in complexity, and delivery of safe, quality, efficient and timely healthcare has become an indispensable necessity.

The US Institute of Medicine report, *To err is human: building a safer health system*, was a rude awakening to the devastating reality that healthcare was not a safe industry. The status quo was clearly no longer acceptable, and it became clear that an intervention of global magnitude was of paramount importance.

Following the World Health Assembly Resolution (WHA55.18) in 2002 that urged Member States to 'pay the closest possible attention to patient safety', the World Alliance for Patient Safety (WAPS) was launched.

I immediately joined, initiating action by representing Egypt as a Patient Champion in the 'Patients for Patient Safety' strand of the work of WAPS. A team of Champions from all around the globe met in London in 2005 and drafted the London Declaration, which drew immense attention to the role of patients and their families in shaping healthcare, and introduced to many countries the voice of the patient which, until then, was not recognised in many parts of the world.

Building on the compassion and the momentum generated at this landmark event, patient and consumer engagement in shaping healthcare system delivery became recognised as a matter of utmost priority, particularly in developing countries where resources are limited, infrastructure is suboptimal and

systems are shaken by a fluctuating economy amidst political upheaval and regional instability.

Egypt, having been the focus of the world over the past decade for its significance in the Middle East and its historical experience in the instigation of a wave of revolutions that swept through the Middle East, was no exception.

I have had the pleasure to represent and lead a team of compassionate volunteers, whose primary goal was to improve the circumstances surrounding patient care, to raise the voice of the patient and to mitigate adverse events to which patients are exposed during the process of healthcare delivery in Egypt.

Recognising the dire circumstances surrounding healthcare delivery, particularly in under-resourced areas of the country, and building on the pressing need for immediate intervention, we started a group of volunteers in 2002. The group was independent from the start, although it was affiliated with the Egyptian Red Crescent group dedicated to improving patient services.

Having an independent status allowed the team to freely participate in healthcare delivery service observation, analysis, and planning, as well as fund-raising, without having to worry about risking conflict of interest. Our team started with two members and expanded to include 50 members, most of whom had no medical background whatsoever. It was critical that the driving impetus would be guided by a consumer perspective rather than a provider lens.

Our work started by via an initial path of observation and situation analysis in public, governmental and teaching hospitals, known to serve a vast majority of poor, underprivileged and mostly uneducated patients. Our aims were mainly to advocate for raising the voice of the patient and to identify and address lapses in healthcare, highlighted from the patient perspective.

After initially approaching hospital administration and carefully clarifying our objectives to provide constructive assistance and support, we entered hospitals viewing the situation from a consumer perspective. Our team carefully noted problems that were central to the delivery in safe healthcare— which was glaringly lacking in hospital settings.

A myriad of problems was identified, related to infrastructure, hospital management, communication lapses, breaches of infection prevention and control policies, lack of trust between patients and providers, and a general undermining of patients by providers.

Using a collaborative, constructive, systematic approach, we managed to build a platform of trust, inviting patients and providers on board. Both parties considered us neutral and provided, slowly but surely, a hand to join the team. Our efforts led to many achievements, ranging from patient capacity building to leadership engagement in patient and community support. Unexpectedly, but quite importantly, our team gradually became involved in highly technical details, such as the implementation and teaching of infection control practices.

It is with pleasure that we share our experiences in Egypt, hoping to advocate for the engagement of consumer groups in shaping health care delivery, and in partnering with providers towards the ultimate goal of delivering safe and effective healthcare for all

Nagwa Metwally will be talking about patient engagement in Egypt and taking part in a discussion on patient centred care at 2:00pm on Thursday 11 October 2018 during day 2 of the World Hospital Congress.

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