

## Truth telling in reproductive medicine



The concept of truth telling is now widely accepted in end-of-life care and oncology and has been defined as the communication of what is known or believed to be true without deceit or falseness (1). Increasingly, it is being seen as a basic moral principle or value in several branches of medicine reflecting the change in the traditional relationship between the charismatic sole practising doctor and a sick passive patient. There currently is a considerable emphasis on informed consent, so an objective patient has enough information to agree to medical treatment (2). However, the disparity between a benevolent authority and the preservation of the patient's autonomy is difficult to resolve in many situations where there is a considerable knowledge gap and the patient is likely to be in a vulnerable emotional situation, aggravating both the power asymmetry and the capacity to process information (3).

Truth telling aims to be a two-way process to build, rather than just stating, the truth and helping patients to make informed decisions during a confusing emotional time. This process will vary considerably between countries and cultures, where in some situations an individual demands complete autonomy, while in others families and communities want to be involved in decisions. Traditional views of autonomy see individuals as capable of making rational independent decisions based on facts. However, few of our patients are in that situation where the prognosis relevant to their circumstances may be unclear to the treating team, the patient is usually in a partnership with another individual, they may be weighed down by the financial and social circumstances of their choices and receiving disparate information from friends, social media, and the internet.

How, for example, do we give advice to a patient in her 40s who wants to only use her own eggs and has a chance of pregnancy <1%? Should we encourage her in her conviction that she still has a chance of a live baby even though the physical, emotional, and financial burden will be substantial? Do we discourage her with harsh facts about the overwhelming probability of failure? What the patient hears may be different from what we think we are communicating. We may think we are sharing one fact (virtually no chance of live birth) while the patient hears something else (a definite chance of success). Also, what about patients with recurrent implantation failure who, to keep hope alive, demand expensive testing and interventions with no clear evidence base? What about the patient who wants to try some of the adjuvants, both cheap and expensive, that have been criticized as being unproven? Are we to be brutally honest and say that they have no chance of success or are we to be compassionate and share that, in trying these approaches, there may be some hope, thereby testing our integrity?

In medicine, we have two fundamental principles of doing good and not doing harm (beneficence and nonmaleficence), which are often invoked. It has often been pointed out that there is no similar emphasis in medicine on truth telling

(veracity) in any of the oaths doctors honor or even in the American Medical Association Principle of Ethics (4). While we are excellent at seeking the best for our patients, we are often not competent bearers of bad news and we frequently are uncertain of prognostic outcomes. We do not want to tell lies, but want the freedom to hold back from delivering a blunt paternalistic answer.

It is very difficult for our team members to deal with patients whose doctors have given them a generally unreachable hope of success. The doctor may be concerned that patients will move clinics to find someone who gives them a better outlook and this practice often is encouraged in our competitive medical systems by offering popular but unproven therapies and opinions. The nurses who have regular contact with the patients want to foster hope for them. The laboratory wants to invoke new technologies and approaches to get a better outcome. The clinic manager is aware that blunt honesty may lead to a lack of financial success. The marketing organization wants to present an optimistic and competitive reputation for the organization. The counselor wants to provide comfort in times of crisis. In this environment, we need to find a way to tell the truth but not to cause harm to the patient or the team. To do so, we often seek help from outside agencies.

Regulation of assisted reproductive technology seeks to ensure safe, transparent, and honest medical practice, but in doing so, it promotes competition based on alleged pregnancy results between clinics that are often not comparable. Professional societies have practice guidelines for treatment that encourage medical practice based on evidence, but these are often ignored, outdated, or distrusted. Journals seek to publish research to get better practice, but the papers are often criticized as not relevant to individual patients, may be flawed, and occasionally are outright false. So how do the clinic and staff who aspire to high integrity in their medical practice deal truthfully with patients in such a wide variety of circumstances?

I believe that the profession needs honesty, independent of the financial consequences for the treating doctor or organization and one that allows for dynamic, iterative, and interactive discussion, seeking the best outcome for the patient. To achieve this goal, the doctor is best served by a team that has a consistent, agreed culture of compassionate truth who agree on a common message for the patient based on their best interest. Members of the team must be empowered to challenge and debate clinical and scientific practices that do not serve the long-term benefit for the patient, while respecting the autonomy of all involved. This demands inspiring and consistent leadership, which then is reflected in optimal patient care. The team is best served by quality practices, relevant education, and updated evidence from appropriate research and observation. Truth "tellers" must also be truth "seekers"! There may be a role for a frank discussion between patient and doctor at the beginning of treatment as to what amount of information the patient really wants on their journey. They may want harsh truths that, while discouraging, may aid their decision-making or they may not want to hear bad

news, including the team's doubts about success. Once a fertility patient is well informed, there may be some space for the right not to know, or at the very least the right not to be reminded of certain grim statistics. Similarly, patients may appreciate doctors acknowledging the limits in their knowledge, which is part of truth telling. Sometimes the right answer is "we don't know," or "there's not enough research on this particular point," or even "this is a matter of controversy within the field." All this demands allocation of our precious time.

We work in a discipline whereby we are not only medical and scientific professionals, but also the subject of intense scrutiny by social, cultural, and political movements (5). The people who visit us are often in good physical health although many are emotionally challenged through lacking a child to complete their fulfillment. Some may have been trying to get pregnant for years and feel that in vitro fertilization is their very last chance, either because they are running out of time or because they are spending the last of their savings to have a child whom they think is necessary to have a full and meaningful life. That desperation may lead us to give people false hope and unnecessary treatment but also offer less than optimal care. Our patients deserve honesty, empathy, and integrity from us. We need to work out how

to have an open discussion to help patients arrive at an informed decision without acting paternalistically on the one hand and yet being so neutral on the other that we cannot compassionately share the journey ahead of them.

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