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Can a health professional represent patient views: Industry response

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To the Editor:

The writer raises some interesting points. It is evident the “health professional as patient” faces several challenges that are of a general nature and not specific to Health Technology Assessment processes. As she articulates, the “health professional as patient” may be faced with a range of responses including the assumption that the “patient” knows everything relevant to their condition and does not need support, or somehow feeling the health professional has “let the side down” by becoming a patient.

In regard to HTA processes specifically, there is increasing recognition of the importance of quality, balanced input from patients, patient advocates, and in some situations, carers. The fact that the health professional concerned may, by virtue of professional knowledge and experience, have an advantage in expressing that input should not be seen as a reason for preventing or ignoring that input. On the contrary, provided the HTA process seeks and uses patient (and carer) perspectives for the right reasons, this should be a positive. The “right reasons” include gaining a more thorough understanding of what it is like to live with the condition in question, clarifying what changes in disease-specific outcome measures really mean, and the strengths and disadvantages of current treatments.

Conducted with these objectives in mind, patient and public perspectives can be a positive contribution to good HTA. There is no place for the “this treatment must be recommended because I need it” style of input. Indeed, that can be seen on occasions from health professionals and patients alike. What is needed is a positive and supportive HTA process that makes clear what input is desired from both patients and health professionals, and how that will be used. When this is operating and individuals understand what is useful, they should feel that their input is both welcome and valuable to the HTA process and its outputs.

From an industry perspective, our desire is to see the full range of perspectives considered in HTA processes, with objective assessment that considers all stakeholders views and inputs. This requires a transparent system and education for all stakeholders, including patient advocates and interested health professionals.

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Response: I know how you think, so I can help

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To the Editor:

I do think all of us are clear that (i) we don't want to be sick, and (ii) being a patient is a matter of time, so almost anybody could walk away from the disease journey. I do really subscribe to both statements, although, unfortunately, I am living with an incurable and rare form of malignant tumor, aka cancer, since the year 2001. Moreover, I have been on daily chemotherapy for the past 4 years and have been exposed over time to three major surgeries and six different types of chemotherapy.

Despite cancer, recently, I have been quite busy on learning how to manage an intensive insulin therapy needed to live with postsurgical diabetes. All these maladies have been compatible to more than 500 lectures given in the past 3 years in different parts of the world, sitting in more than 30 government and nongovernment positions, having a CEO position in a \$2M annual budget Foundation for 12 years, creating several projects, enjoying a marriage of more than 20 years which includes two wonderful full-of-life boys, and writing over 200 papers of all kinds, including three nonfiction books and a novel. Am I a kind of superman? No way, I am a cancer patient! I know that life is short and is a gift that deserves to be lived intensively and with joy. Let others have the problems; let's focus on the solutions.

I don't care if I have done much or little, but I care about fulfilling a moral obligation to share my painful experience with others because what is happening to me might happen to you anytime. And, if that thing happens to you, I can assure you that you'd like to benefit from all helpful experiences at hand. Mine is one of them. However, my moral obligation to share personal experience is grounded on three major factors. First, it fits with my aim of preserving human dignity in front of the stigma surrounding cancer patients. Nobody wants to talk about it, but the stigma is always there. Second, it fits with my professional sense of purpose. I chose to be a doctor because I wanted to serve people facing vulnerability. Third, I have received from society more than I deserve and more than I could give back. I have an almost free medical care, including the latest innovations; an almost free medical school, a free 4 years of doctoral studies at Harvard, an almost free PhD in sociology, an interesting experience in government, etc. Despite an unfair and painful disease, I have been a fortunate man. After all these experiences, you have the moral duty to try to help others.

Finally, being a doctor, working in an academic setting, having experience in HTA, and being a patient puts me in a good position to bridge the gaps over prejudice and misunderstanding. Basically, I know how the stakeholders think and feel because I could easily walk in everybody's shoes. Look at your shoes and you can see my feet.

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Who can and who should represent the patient?

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To the Editor:

Why can it be difficult for healthcare professionals to be patient group representatives? First, we will try to clarify what is meant by *representing* a patient group and what is meant by being a *patient*.

Representing a patient group can mean to present a particular expertise, that is, to explain how it is to be a patient with a particular condition or disease. However, it can also mean to speak up for, argue for, or demand (in power-like relationships) on behalf of a certain interest group. Moreover, it can mean to enter into dialogue and negotiations on basis of one's unique experience and perspective.

Correspondingly, what does it mean to *be a patient*, and does an additional role as a healthcare professional alter the patient role? In other words, are healthcare professionals who have a disease patients who happen to be health professionals, are they "sick professionals," or something else?

A patient is normally defined as "the one who suffers" and who needs help and assistance from healthcare professionals. Accordingly, the patient has experience of illness and can guide decision makers toward using relevant endpoints and outcomes. However, a patient can also be seen as a person with a particular experience of the treatment system, social expectations, and power relationships (according to his or her *sick role*). In this latter *patient role*, a patient representative may aim at empowerment, autonomy, and improvement of treatment systems. A third conception of the patient may be as a client or consumer. In this perspective, a patient representative may be one who demands more and better services for his or her group.

In the first two conceptions of *patient*, it may be difficult for a healthcare professional to be a representative. As Dr. Packer herself points out, her experiences as a patient differ from those of other patients. Healthcare professionals behave differently toward her, and she is expected to know more

about the disease and the healthcare system than ordinary patients. Hence, the healthcare professional may have different experiences of being a patient and of the healthcare system than the patients he or she is supposed to represent. But then, if patients are conceived of as consumers, a healthcare professional may be a brilliant representative, as she or he will have more knowledge about the disease, the healthcare system, and about potential diagnostic and therapeutic options.

Another reason why health professionals can find it difficult to be patient group representatives is that patient groups are stakeholders who to some extent define themselves in contrast to other stakeholders, such as health professionals and decision makers. There is a power relationship between patients and health professionals. In such cases, patients may wonder whether a professional really promotes the perspective and interests of the patient group, or whether she or he is influenced by her or his role as a professional. Hence, challenges with trust and conflict of interest may hinder some professionals from being elected as representatives. Professionals as representatives could also inadvertently alienate other patients by moving perspectives and terminology away from the experiential sphere of "lay patients." On the other hand, professionals who "switch perspective" may be brilliant representatives but may get problems with their professional community and identities.

Hence, there are some good reasons why health professionals may well be patient group representatives on decision-making fora. For several equally good reasons, it can be difficult for healthcare professionals to represent patients well. Our conclusion is that healthcare professionals *can be*, but not that they *should be*, patient group representatives. The decision should be up to the lay patients.

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