**Different context, similar motives: external influences on motivation.**

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The findings of Luchtenberg et al (2015) regarding patients’ motives to enroll in trials are informative, and young peoples’ recommendations instructive. My experience with patients (including 18-24 year olds) in a South Asian (Pakistani) setting substantiates these findings. The most common reason in my research is personal benefit, with “conditional” altruism, (McCann, Campbell et al. 2010) a close second. In Luchtenberg et al’s research, personal benefit and helping others were the two main themes as well, although the patients belong to a different ethnic group – White British. This emphasizes that most enrolled patients have similar motives, even though they live in different geographic locations and social contexts.

Luchtenberg et al (2015) however, do not consider the factors that influenced these patients’ motives to enroll. Although questions relating to how and why patients enrolled were asked, specifics regarding influencers are not available. My research shows that there are influencing factors on patients’ motivation, arising from their social context or specific circumstances. Some of these are:

* Family influence: the influence of the family on patients’ motivation is important, though patient’s should be able to decide autonomously – I discuss this phenomenon elsewhere (Malik 2011).
* Nature of the trial: whether the trial was testing a new intervention i.e. drug or a diagnostic test or if it was an epidemiological study.
* Socio-economic status of the family: affordability and availability of treatment for their disease.
* Progress on available treatment.
* Patient’s experience with previous trials.

Though altruism is very difficult to clarify (Jansen 2009), in Luchtenberg et al’s research a few participants’ key motivation was only to help other, future patients, parents and doctors. However, Luchtenberg et al (2015) do not mention whether this motive was influenced by external factors. My experience is that other factors, such as the family or the nature of the trial has an influence. In trials that are testing new drugs, patients enrolled if they consider it would benefit themselves or it would benefit themselves *and* others. But occasionally, patients enrolled, especially in trials that are developing a diagnostic test/equipment or epidemiological study, out of desire to help other, future patients, and so their sole motivation was altruism. However, there are patients, such as the one I observed, who wanted to enrol in a similar research for altruistic reasons. But she was discouraged by her brother who was of the opinion that if this research is of “no use to my sister” then “why waste time”. Although she was keen to help other patients, her brother’s decision prevailed and she declined enrolment.

Often altruism is not a primary but a subsidiary motive (Jansen 2009). Luchtenberg et al’s (2015) participants were often motivated by a combination of personal benefits and helping others. In my research too, a few patients, especially those with some knowledge of science, realized that their participation will not only benefit themselves but also other patients. Thus grounded in “*insānī humdardī”* (sympathy for fellow humans) their motive was to benefit “*Khalq-e-Khudā”* (humanity) as a corollary. Nonetheless this conditional altruism was important to them.

Both, patients whose primary motive was altruism, and those who acted on altruism as a subsidiary motive, viewed taking part in research as a form of *sadaqah* *jāriyah* (ongoing charity). Their motives were influenced by their religious beliefs. In Islam it is generally considered that the rewards of *sadaqah jāriyah* continue in the Hereafter: "When a man dies all his good deeds come to an end except three: Ongoing charity *(Sadaqah Jāriyah*), beneficial knowledge and a righteous son who prays for him” (see also IOMS 1981, Khattāb 2007, An-Nasai n.d). It may be that patients motivated by personal benefit also realize that research is serving a wider purpose – that of benefiting society and , by extension, themselves as well (Kim, Schrock et al. 2009), even if the benefit may be enhanced self-esteem or enrichment in the patient’s life. These findings cohere with Luchtenberg et al’s (2015) conclusions.

My findings regarding personal benefits echo Luchtenberg et al’s (2015) results, and show that the most prominent motive to consent to research were the personal benefits accrued, during and from research. That is, both the trial process and trial intervention were considered useful by patients. Similar to Luchtenberg et al’s (2015) findings, better treatment options (“new” treatment), better and closer monitoring of their condition, and better care by physicians were given as the main reasons. Additional reasons given were that physician-researchers had more time to discuss patient’s illnesses, there was easy accessibility (especially to professors), free testing and, at times, reconfirmation of diagnosis. The fact that these collateral benefits would be available to patients irrespective of arm of the trial they are in, motivated patients to decide in favour of enrolment in the research (King 2000).

In trials that were testing a new medicine, patients who had failed on available treatments hoped the trial medicine would provide some therapeutic benefit. Patients saw this as a turning point in their illness (Cox 2002, Kim, Schrock et al. 2009). Some were encouraged by their family (especially husbands) if enrolment meant lower cost or “free treatment”. There was also an occasional patient who had benefited from a previous trial and was convinced that this “new” (trial) medicine will also treat her disease.

When clinical care and clinical trials are conflated, a dilemma arises – that of therapeutic misconception. Although it is important to dispel therapeutic misconception it is important to view it in the context in which research is conducted. In circumstances where, outside the trial, the drug is either not available or the cost of treatment is high, and therefore out of many patients’ reach and the available treatment in government hospitals is limited, trial enrolment may be a rational choice(Mfutso-Bengo, Ndebele et al. 2008)

Therapeutic misconception is not confined to developing countries; as the authors report, it is experienced in the developed world too. What appears to be common between the two “worlds” is that the patient “transfers to the research setting the presumption that obtains in ordinary clinical treatment: that the physician will always act only with the patient’s interests in mind” (Appelbaum 2002:22). This is reinforced by the fact that, traditionally, medical research has been understood as contiguous with clinical practice. Patients start a prescribed treatment in the clinical setting believing in its efficacy. This extends into the research paradigm, where the environment is also the same. It is plausible that when patients are informed of another available option – medical trials – in which a “new” (trial) medicine will be given, they interpret that as a “new treatment” for their condition (Kim, Schrock et al. 2009). Luchtenberg et al (2015) consider “therapeutic optimism” a better phrase that reflects patients’ hope and optimism to cope with, or definitively treat, the illness. Although it is important to dispel therapeutic misconception, separating clinical therapy from clinical trials is not easy, especially when patients find they benefited from enrolling in a trial, previous or present.

In summary there is therefore a set of common motives that transcends borders of ethnicity and state. However there are factors that influence motivation, changing the motives’ relative importance. These factors, discussed above, are also fairly consistent across cultural divides.

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