

The construct of breast cancer risk perception: need for a better risk communication?

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Abstract

Breast cancer risk assessment and communication are much neglected aspects of women's health care. Breast cancer is the most prevalent cancer-related disease that touches the deepest of a women's feelings and the subject thus attracts much of the attention of the media. Disease prevalence and media coverage are the roots of inappropriate breast cancer risk perception. Many women overestimate their personal breast cancer risk. Inappropriate risk perception precedes inappropriate health behaviour and it is pivotal to understand the underlying mechanisms in order to plan intervention. Whether interventions such as patient education through counselling and objective risk assessment are effective in restoring inappropriate breast cancer risk perception remains a question unanswered, but the tools to measure breast cancer risk are available and were validated.

Key words: Breast neoplasm, communication, media, patient education, perception, risk assessment.

Introduction

Perceived risk is defined as one's belief about the likelihood of personal harm (Weinstein and Klein, 1995). Personal health risk perceptions may be an important determinant of specific health-related behaviour and it is the pivot in a number of theoretical models on health behaviour, the Health Belief model being generally well-known (Janz and Becker, 1984). It is therefore clarifying to explore the elements underlying risk perception and to study the relationship between perceived risk and consequent health-related behaviour in order to communicate health risks to the general public in a way that health-related behaviour is changed for the better (Lipkus *et al.*, 2000). This review summarizes present knowledge on breast cancer risk perception and risk communication, two topics that are inherently related. The subject of breast cancer risk assessment and risk communication is well researched but lacks implementation in daily clinical practice as physicians are hardly familiar with it.

Breast cancer worry

How often does one hear women say: "It seems to me breast cancer is all over the place: in my family, in my neighbourhood, in the newspapers and on TV". Indeed women worry a lot about getting breast cancer more than about any other disease (Wang *et al.*, 2009). Age-adjusted incidence of breast cancer indeed has increased over time (Horner *et al.*, 2008). There is a high frequency of thinking about breast cancer probably triggered by events in our immediate environment, the so-called "social construction of the breast cancer epidemic" (Lantz and Booth, 1998). Most common triggers reported are media reports, daily social contacts, and meeting someone who suffered breast cancer (Mc Caul *et al.*, 1998, Montgomery *et al.*, 2003). Societies in Western Europe characterised by an ageing population with a higher prevalence of breast cancer, a recent introduction of breast cancer screening programmes associated with an increase of breast cancer diagnoses, and a widening of the public debate about breast cancer

as a result of improved treatment outcome and an increasing number of breast cancer survivors are ideal grounds to nourish this availability heuristic. When people worry about breast cancer they most often think about their personal risk, about family or friends affected, and the high prevalence of the disease. Lerman *et al.* reported that 30% of women with first-degree relatives who had breast cancer said that they worried about breast cancer so much that it interfered with their daily functioning and quality of life (Lerman *et al.*, 1993).

Breast cancer risk perception

Women commonly misjudge their breast cancer risk, overestimating their lifetime risk and cancer-related death risk of a significant degree (Mc Caul *et al.*, 1998; Bunker *et al.*, 1998). In one study women between 40 and 50 years of age overestimated their lifetime risk by 12-fold and their short-term risk of dying from breast cancer by 22-fold (Black *et al.*, 1995). Only 7-37% of women, depending on the demographics and the education level of the women studied, had a realistic notion of the population lifetime breast cancer risk. The proportion of women that overestimate their risk of breast cancer varies widely between 50-90% depending on the population studied and the way information was obtained (Lerman *et al.*, 1994; Smith *et al.*, 1996; Alexander *et al.*, 1996; Bowen *et al.*, 1997; Herbert-Croteau *et al.*, 1997; Dolan *et al.*, 1997; Woloshin *et al.*, 1999). The mean perceived lifetime risk of developing breast cancer in studies varies between 30 and 46%, much higher than the real lifetime risk of 12%. (Bowen *et al.*, 1997; Davids *et al.*, 2004; Fagerlin *et al.*, 2005). Women in particular those who are young and those with a family history of breast cancer have unreal risk perceptions (Evans *et al.*, 1993; Daly *et al.*, 1996; Zakowski *et al.*, 1997; Davids *et al.*, 2004; Katapodi *et al.*, 2004; Haas *et al.*, 2005).

Factors underlying breast cancer risk perception

Breast cancer risk perception is influenced by both medical (subjective and objective) (Lipkus *et al.*, 2000) and psychological factors (Gerend *et al.*, 2004). Medical factors include family history and age. There is body of evidence that links a family history of breast cancer to perceived risk. Notwithstanding women's risk of developing breast cancer increases with age, older women perceive themselves as less susceptible to breast cancer than do younger women (Wilcox and Stefanick, 1999; Katapodi *et al.*, 2004). There is a well documented discrepancy between subjective and objective medical risk (Katapodi *et al.*, 2004). Objective medical risk

is measured in terms of absolute risk (e.g. "How likely is it that one will develop breast cancer in a lifetime?") and direct comparative risk (e.g. compared with other women of the same age, how likely is it one will develop breast cancer?"). Objective medical risk can be calculated by various mathematical tools based on the Gail model (see risk calculation and communication, Gail *et al.*, 1989).

Psychological factors that influence breast cancer risk perception include the perceived nature and the heuristic processing of breast cancer as a health threat. Regarding the nature of a threat it is shown that the more prevalent, severe, devastating, unexpected, difficult to control the nature of a threat is, the more it is associated with higher risks of perception (Slovic, 1987). Heuristic processing of a threat involves two cognitive functions: i) the availability heuristic judging the probability of an event by the ease with which examples of that event come to mind (for example, experience with a threat – be it personal, via family/friends or via the media – increases the availability of the threat and, as a result, its perceived likelihood (Weinstein, 1987); ii) the representativeness heuristic judging the probability of an event by its similarity to events with comparable features (for example, the belief that one is similar to the type of person who develops a specific disease is associated with a higher risk perception to that disease) (Lek and Bishop, 1995). This specific factor – perceived similarity to the person who develops breast cancer- is the single strongest correlate of perceived breast cancer risk followed by the perceived prevalence of breast cancer and the vicinity of a relative/friend with breast cancer (Gerend *et al.*, 2004).

Fear of breast cancer partly results from being confronted with a potentially lethal disease. The first question that comes up in one's mind once diagnosed with breast cancer is: "How long have I to live? What are my chances of surviving?". Health care professionals should at some stage in the follow-up of breast cancer treatment picture the risk of dying of breast cancer within a broader context taking into account other real risks such as death from cardiovascular disease or car accident. Non-oncological diseases as these which pose a much greater risk to a woman's life with a worse prognosis are underestimated and their threat is perceived to be low (Phillips *et al.*, 1999). Again this disproportionate fear of breast cancer relative to other non-cancer diseases is irrational.

Media coverage and worry about breast cancer

It is a well accepted statement that the media has a substantial effect on a women's health perceptions

(Frost *et al.*, 1997). We referred to availability heuristic as one of the mechanisms that influences one's perception of risk. Availability heuristic probably mediates the heightened personal and general vulnerability perceptions induced by media coverage of health topics. Women who had been exposed occasionally to programs on breast cancer on TV were twice (95% CI 1.1-3.4) more likely to be very afraid of breast cancer. Depending on the degree of media exposure the odds ratio of expressing high levels of fear of breast cancer increased to 7.5 (95% CI 2.4-23.8) (Lemal and Van den Bulck, 2009). Moreover media coverage of breast cancer is over-represented (Gerlach *et al.* 1997; Blanchard *et al.*, 2002) and frequently involves personal stories with accent on emotional experiences (Atkin *et al.*, 2008) to give it a dimension of "newsworthiness" (Lantz and Booth, 1998). The same has been found in the popular written press where stories on breast cancer misrepresent the age distribution of the disease, focusing on atypical cases of early-onset breast cancer and their often dramatic social impact. (Burke *et al.*, 2001). These magazines are (were) known to be an important source of health information (Meissner *et al.*, 1992; O'Keefe *et al.*, 1998) certainly before the era of the internet. The emphasis on young age found in popular magazines follows women's misperceptions about risk and may nourish them. The effect of risk factors related to breast cancer is another item that is miscommunicated by the popular press. In 1996, many women were concerned after publication of a review of the association of breast cancer and hormonal contraceptives which stated that the risk of breast cancer was increased by 20% in users (Collaborative Group on Hormonal Factors in Breast Cancer, 1996). If the risk was communicated as an absolute risk increase from 16 to 18.7 per 10 000 women or one additional breast cancer diagnosis per year among 3700 women taking oral contraceptive, risk perception would have been totally different. Similarly, the Women's Health Initiative Study results of hormone replacement therapy as a primary prevention trial of chronic diseases such as cardiovascular disease were summarized in the media as a 26% increase of breast cancer in users being the main message (Rossouw *et al.*, 2002). Again if the risk was communicated in terms of absolute risk (19 additional breast cancer for combined therapy and 5 for estrogen-only therapy per 10 000 user-years) the message would have been more shaded.

Pleas made by the medical community (Woloshin and Schwartz, 2002; Schwartz and Woloshin, 2004) and guidelines proposed by journalists (Russell, 1999; Brody, 1999) for media to present health issues in a scientifically justified and balanced way

have not filtered through yet as they are inferior to commercial interests.

Breast cancer risk calculation and communication

With respect to the autonomy of women seeking medical care, providers should inform their patients to that extent that they feel comfortable in making decisions about their care. With regard to breast cancer risk perception and how to respond appropriately in terms of preventive strategies, women need accurate counselling. Communicating health risk with patients is assumed to be a part of routine care/education provided by health care professionals (Sabatino *et al.*, 2007). In fact receiving information on health-related issues from health care professionals in particular information about cancer risk is very much appreciated by patients (Schwartz *et al.*, 1999; Buchanan *et al.*, 2005). Very little is known about how breast cancer risk is assessed in daily practice. A study on risk communication defined as a discussion on health behaviour, participation in early detection or other preventive health strategies revealed that risk was discussed in only 26% of primary care visits and that risk was presented numerically in only 3% of visits (Kalet *et al.*, 1994). Lack of knowledge and a busy consultation time schedule are obvious reasons why physicians fail to deliver effective health risk information. Breast cancer risk information is important information to be communicated with patients for a number of reasons. In the first place it is an attempt to correct inappropriate perceived risk. Secondly, evaluation of risk status may influence health-related decisions about screening (Pichert *et al.*, 2003), chemoprevention (Howell A, 2008), referral for genetic counselling and testing (Nelson *et al.*, 2005), and even prophylactic surgery (Evans *et al.*, 2009). There are a number of tools available that may be worthwhile in facilitating communication about breast cancer risk (Euhus, 2001; Jacobi *et al.*, 2009). Providing women with a personalized numerical breast cancer risk estimates on the one hand could bring the message much more clearly than general messages on breast cancer risk (Skinner *et al.*, 1995). However, focusing on a single disease-specific risk could overemphasize that risk disproportionately to other even more important health issues (Schwartz *et al.*, 1999).

The risk of developing breast cancer of 1 in 10 is a statistic that is often used in the popular press as it is appealing and frightening at the same time. It is even more frightening to know that the figure is on the rise. Unqualified quoting of such statistics equals disinformation of the public. However I do not see initiatives to ease the public opinion most probably

out of fear that rectification of this sort of disinformation won't help breast cancer screening programmes. From an ethical point of view this sequence of events is most questionable.

So how should one counsel a woman with regard to her breast cancer risk? It is not an easy task and it requires a sense of numeracy (quantitative literacy) on the patient's part. Low numeracy is pervasive and constrains patient choice, limits access to treatments, reduces compliance with therapy, and impairs risk communication as it is associated with difficulty in understanding and assessing probabilities of risk and risk-related information, especially when that information was presented to them in a quantitative, numerical format. (Schwartz *et al.*, 1997; Lipkus *et al.*, 2001; Davids SL *et al.*, 2004; Nelson *et al.*, 2008). Intervention trials designed to improve communication on quantitative data about health risk or treatment benefit showed variable results with regard to risk perception (Woloshin and Schwartz, 1999; Vernon, 1999). Graphic displays on understanding health risks are of general benefit and may be especially helpful to those who are least numerate (Ancker *et al.*, 2006).

As mentioned earlier there are a number of breast cancer risk assessment tools available. An overview of these tools is given by Jacobi *et al.* who, running the models for two healthy women from BRCA-negative/unknown status families, found that the Tyrer-Cuzick and the BOADICEA model were most appropriate in predicting breast cancer risk (Jacobi *et al.*, 2009).

The most basic method of communicating breast cancer risk involves the use of the SEER data (Surveillance, Epidemiology, and End-Results), the most exhaustive cancer database presently available on the internet (<http://seer.cancer.gov/statistics/>). A lifetime table analysis of the cumulative incidence of breast cancer in the population will help to explain the 1 in 8 (12%) lifetime risk for breast cancer (Table 1). From Figure 1 it is clear that at the age of 39 a woman has a risk of 1 in 1000 to contract breast cancer in that calendar year. For a woman at the age of 69 this risk has increased to one in 250 for that year. Table 1 shows us that a woman at the age of 35 has a 1 in 115 risk of getting breast cancer in the next 10 years. This risk increases with age becoming 1 in 40 by age 50, 1 in 25 by age 65. This type of age-specific data should take care of any disproportionate fear of breast cancer amongst women. These life table estimates are population-based data and represent averages that do not take into account patient-specific risk variables such as age at menarche, age at first pregnancy, a family history of breast cancer, etc. Ideally an individual should be counselled about her risk of developing breast cancer taking in con-

sideration not only her age but also her risk factors. The most important risk factor for the development of breast cancer apart from age is a positive family history for breast cancer (Dumitrescu and Cotarla, 2005).

The calculation of a more personalized objective medical risk is based on the Gail model (Gail *et al.*, 1989). The original Gail model is a statistical model based on relative risk conferred by specific risk factor populations defined in the Breast Cancer Detection Demonstration Project, a large American mammography screening trial between 1973 and 1980. To date a modified version linked to updated SEER data is known as the "Breast Cancer Risk Assessment Tool" and can be found on the website of the National Cancer Institute (<http://www.cancer.gov/bcrisktool/>). Risk is expressed as a 5-year and a life-time absolute and comparative average risk. Risk factors that are taken into account are age, age at menarche, age at first live birth, number of first-degree relatives with breast cancer, and number of previous breast biopsies. Other risk factors, such as age at menopause, dense breast tissue on mammography, use of hormonal contraceptives or replacement therapy, high-fat diet, alcohol intake, low physical activity, obesity, or environmental exposures, are not included in risk estimates as they do not increase the accuracy of Gail model. The modified Gail model has been validated to provide accurate estimates of breast cancer risk of women without prior history of breast cancer (Costantino *et al.*, 1999). In contrast to the Gail model which incorporates basic information on family history limited to the number of first-degree relatives only, the Claus model provides age-specific breast cancer risk estimates based on a more extensive family history including first- and second-degree relatives as well as the age at the time of diagnosis of breast cancer (Claus *et al.*, 1994). Risk is presented as a probability of developing cancer at a certain age with five-year increments up to the age of 79. BRCAPRO, also known as the John Hopkins Bayesian model, is another statistical tool which analyzes family history information on breast and ovarian cancer even more extensively in order to determine the probability of a BRCA1/BRCA2 gene mutation in the proband (Berry *et al.*, 2002). To do so the model uses the observed incidences of breast and ovarian cancer among BRCA1/BRCA2 gene mutation carriers and noncarriers. Given this BRCA1/BRCA2 gene mutation probability the risk of getting breast cancer is estimated. The accuracy of this estimation is based on the knowledge of the exact mutation frequency of the BRCA1/BRCA2 gene in the population this individual belongs to. The BRCAPRO Model was further refined by incorporating non-genetic risk

Table 1. — Probability of women developing breast cancer, all ages, all races, SEER data 2004-2006.

| Cancer Free Age | Age 25 | Age 30 | Age 35 | Age 40 | Age 45 | Age 50 | Age 55 | Age 60 | Age 65 | Age 70 | Age 75 | Age 80 | Age 85 | Age 90 | Age 95 | Age 95+ |
|-----------------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|--------|---------|
| Age 20 | 0.010 | 0.057 | 0.192 | 0.491 | 1.059 | 1.909 | 2.940 | 4.180 | 5.643 | 7.205 | 8.719 | 10.095 | 11.173 | 11.821 | 12.115 | 12.241 |
| Age 25 | | 0.047 | 0.182 | 0.482 | 1.052 | 1.903 | 2.937 | 4.179 | 5.646 | 7.211 | 8.729 | 10.108 | 11.189 | 11.838 | 12.133 | 12.259 |
| Age 30 | | | 0.136 | 0.437 | 1.008 | 1.862 | 2.899 | 4.146 | 5.617 | 7.187 | 8.710 | 10.093 | 11.177 | 11.828 | 12.124 | 12.251 |
| Age 35 | | | | 0.302 | 0.876 | 1.735 | 2.776 | 4.028 | 5.507 | 7.084 | 8.614 | 10.004 | 11.092 | 11.747 | 12.044 | 12.171 |
| Age 40 | | | | | 0.579 | 1.444 | 2.493 | 3.755 | 5.245 | 6.834 | 8.376 | 9.776 | 10.874 | 11.533 | 11.833 | 11.961 |
| Age 45 | | | | | | 0.876 | 1.940 | 3.218 | 4.728 | 6.339 | 7.900 | 9.320 | 10.432 | 11.100 | 11.403 | 11.533 |
| Age 50 | | | | | | | 1.085 | 2.390 | 3.930 | 5.573 | 7.167 | 8.615 | 9.750 | 10.432 | 10.741 | 10.874 |
| Age 55 | | | | | | | | 1.341 | 2.925 | 4.614 | 6.252 | 7.741 | 8.907 | 9.608 | 9.926 | 10.062 |
| Age 60 | | | | | | | | | 1.646 | 3.401 | 5.104 | 6.651 | 7.863 | 8.591 | 8.922 | 9.063 |
| Age 65 | | | | | | | | | | 1.858 | 3.659 | 5.296 | 6.579 | 7.349 | 7.699 | 7.849 |
| Age 70 | | | | | | | | | | | 1.955 | 3.732 | 5.124 | 5.961 | 6.341 | 6.503 |
| Age 75 | | | | | | | | | | | | 2.007 | 3.579 | 4.524 | 4.953 | 5.136 |
| Age 80 | | | | | | | | | | | | | 1.898 | 3.039 | 3.557 | 3.779 |
| Age 85 | | | | | | | | | | | | | | 1.549 | 2.253 | 2.554 |
| Age 90 | | | | | | | | | | | | | | | 1.166 | 1.664 |

Ref: <http://seer.cancer.gov/faststats/selections.php#Output>

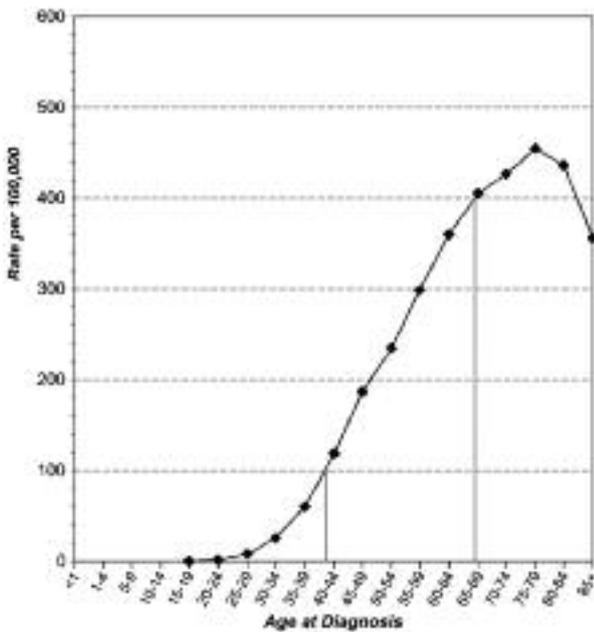


Fig. 1. — Age-specific breast cancer incidence rates, all ages, all races, SEER data 2000-2006.

Ref: <http://seer.cancer.gov/faststats/selections.php#Output>

factors such as age at menarche, age at first born, age at menopause, atypical hyperplasia, lobular carcinoma in situ, height and body mass index, known as the Tyrer-Cuzick Model (Tyrer *et al.*, 2004). Finally, CancerGene is a software computer program

(<http://www8.utsouthwestern.edu/utsw/cda/dept47829/files/65844.html>) that provides an interface for collecting risk factor information needed to run the Gail, Claus, and Bayesian model based risk predictions. The program automatically calculates breast cancer risk and BRCA gene mutation probabilities.

Older models such as the Gail and the Claus model tend to underestimate the baseline life-time risk for breast cancer as they were developed in the eighties and nineties at a time when the incidence of breast cancer was significantly lower (Jacobi *et al.*, 2009). Therefore newer models with updated epidemiological data (NCI Breast Cancer Risk Assessment Tool) and those incorporating also personal risk factors, such as a family history of ovarian cancer, age at menarche, and age at first born (BOADICEA Model (Antoniou *et al.*, 2004), Jonker Model (Jonker *et al.*, 2003), Claus-Extended Formula (van Asperen *et al.*, 2004), Tyrer-Cuzick Model (Tyrer *et al.*, 2004)), yield higher life-time risk estimates.

At present breast cancer risk assessment is an active research topic where in an attempt to improve risk prediction, new models using novel risk factors are developed (Gail, 2009). Adding more information or incorporating new risk factors to the proband will ultimately increase breast cancer risk estimates. This implies that current NICE guidelines regarding threshold risk for increased mammographic surveillance of $\geq 17\%$ life-time risk based on family history risks only, need to be reconsidered (<http://www.nice.org.uk/CG041>).

Worry and self-protective behaviour

The relationship between worry and screening behaviour is not well established. Some researchers believe that excessive worry inhibits whilst others argue that worry facilitates screening behaviour. To date general opinion (evidence level II-3) is that thinking and worrying about breast cancer in women with a realistic perceived breast cancer risk may motivate self-protective behaviour (Leventhal *et al.*, 1999; Consedine *et al.*, 2004; Hay *et al.*, 2006). Trait anxiety on the other hand does not predict self-protective behaviour. However high levels of breast cancer worry in general are said to be uncommon (Hay *et al.*, 2006). A Flemish study though reported high levels of breast cancer fear in about 30% of a random sample of 500 women (Lemal and Van den Bulck, 2009).

Researchers distinguish between content-based worry (i.e. worry about a particular worry domain such as breast cancer) and general worry which is more related to general anxiety. The former is a “constructive” form of worrying and predicts problem solving, the latter is more predictive of avoidant coping (Davey, 1993). This is in accordance with the findings that worry about breast cancer promotes mammography screening uptake (McCaul *et al.*, 1996) whereas anxiety appears to inhibit mammography screening (Kash *et al.*, 1992). Studies examining the association between perceived risk and worry have noted that these variables operate independently in predicting cancer screening behaviours (McQueen *et al.*, 2008; Moser *et al.*, 2007). To date evidence is conflicting as to whether educational interventions as part of breast cancer early detection programs that aim to correct inappropriate perceived breast cancer risk can improve subsequent cancer screening (Vernon, 1999). This is a crucial deficit in the evidence supporting risk assessment and communication, a gap in our understanding of the mechanisms between perceived risk and impact on health behaviour that needs to be bridged before recommendations can be made. An important caveat associated with mammography breast cancer screening is the detection of an increasing number of precursor lesions with uncertain clinical significance. In those cases the ultimate diagnosis remains uncertain and in a climate of defensive medicine these women are often overtreated to anticipate progression into an invasive lesion. Indeed overdiagnosis and overtreatment are inherent to cancer screening (Zackrisson *et al.*, 2006). Clinicians who take care of an increasing number of women with screen-detected ductal carcinoma *in situ* should be aware that many of these women have inaccurate perceptions of the breast cancer risk. In fact women with ductal carcinoma *in*

situ, in spite of a better prognosis, have comparable perceptions of risk of recurrence and risk of dying of breast cancer as women with invasive disease and this causes persistent anxiety (van Gestel *et al.*, 2007; Partridge *et al.*, 2008).

Conclusion

Daily practice indicates that women are worried about breast cancer and overestimate their risk. This review summarizes the factors that play in the construction of breast cancer worry and perceived risk. Although physicians recognize the daily scenarios where women state that they do not wish to perform a breast self-examination out of fear of detecting a nodule as frequently as there are women who insist on having a yearly mammography, they have not taken up the challenge to rectify inappropriate health behaviour. Although physicians spent much time in counselling patients within the curative setting, counselling about preventive health care strategies including health risk communication and lifestyle management should be stepped up as an integral part of patient education. The tools as shown are available. Physicians should start using them in their clinic. As the evidence of benefit is lacking at the moment these actions should be taken within a setting of clinical research.

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