volume 16 issue 3
june | 2014

www.ehps.net/ehp

The European Health Psychologist

Bulletin of the European Health Psychology Society

editorial

Ethics in Research and Practice

"Do good, or no harm"
Hippocrates

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Ethics can't be considered without reflecting on our values. Is health psychology as a body of knowledge and a practice ethical? Do our theories represent and integrate the different values people have? Do our practices benefit more than cause harm?

The world is inhabited by people with different socio-economic backgrounds, cultures and values. However, today our health psychology journals have failed to represent accurately this variety, raising questions on the applicability and generalizability of our findings.

Interestingly, ethical considerations have only been indirectly captured in debates around methodological issues (e.g., meta analysis, see Field 2014; and evidence based practice, see Greenhalgh et al 2014), which involve critical ethical questions about what types of evidence we value. It's unfortunate that we rarely consider such debates as being about the ethics of what we do. We are in danger of professionalising ethics, and thus reducing it to a methodological footnote. It is really quite bizarre that most of us are satisfied with the fact that our research proposal 'passes' the appropriate ethics research committee, and thus we are not really required to formally reflect on the ethical issues again in the course of our research. We all collude in systems that push ethical debate to the penumbra of scientific discourse. Universities, journals, research funding bodies and our professional organizations invest great energy in delineating the ethical boxes that needed to be ticked, but give us relatively little guidance on our responsibility to challenge unethical systems that perpetuate some of the subjects that we study. Just how apolitical can health psychology be is an interesting question. However, as Pericles warns us that just because we do not take an interest does not mean that politics will not take an interest in us.

The most interesting aspect in organising this special issue on ethics in health psychology was how difficult it was to find contributions. Not surprisingly, the contributions that we did find were far from bland. Diana Taut reflects on whether it's ethical to ask people to fight cancer, Marianna Fotaki explores the tangled web around introducing patient choice, and Behnaz Schofield provides a comprehensive overview of informed consent. Finally, Ad Kaptein asks some searching questions about how we apply ethical principles to health psychology research. The remarkable thing about all the contributions is that they ask more questions than the answer, which is what good science should look like.

Highlight of the special issue

Diana Taut (2014) discusses the ethical considerations on cancer treatment. Taut presents the contradictory research evidence on the factors and mechanisms most associated with coping and survival rates in patients with cancer, and criticizes the misinterpretation or misuse of this evidence from the media and marketing. Taut presents as an example the case

of Lisa Bonchek Adams, who decided to make public her everyday experience with cancer using the media. Taut also discusses the pitfalls that the stereotypes of the "survival" personality traits, way of thinking or behaving have for those people who do not possess them, and the subsequent dilemmas for professional recommendations and practice.

Marianna Fotaki (2014) describes the ethical implications of introducing patient choice in the UK. She presents the reasons and the ethical implication of patients' choice in the National Health System in England. Fotaki recommends that patients' choice is not entirely based on their rational decisions about the information provided. Factors like the relationship with the health care provider, the health condition that people have and the extent that this condition influences their cognitive ability, patients' beliefs, cultural values and expectations are even more important factors guiding patients' decision about their healthcare. Fotaki highlights the significance of tailoring the treatment provided to patients' everyday life and needs. She raises the ethical issue of collective responsibility and the treatment missing the opportunity to serve those that might need it more. Fotaki uses the example of Staffordshire NHS to illustrate the ethical and moral implications that market-based health care system has in practice and especially in trust relationships between patients and health care providers.

Behnaz Schofield (2014) describes the principles of autonomous and free choice, as an underlying value of informed consent in health related research. The author also discuss the factors that influence informed consent during the different stages of the research process, and how these factors are related to autonomous and free choice. These factors are participants' understanding of the information provided, which can involve literacy and language barriers, the amount, length and way information is presented, power relationships between the researcher and the participant, and the participants' competence to provide informed consent. Schofield also provides practical tips for researchers and recommendations for research ethics committees, to facilitate autonomous choice during the informed consent process.

Ad Kaptein (2014) discusses the four basic principles of medical ethics and whether and how research and practice in health psychology adheres to these principles. Kaptein reviewed the latest issues of Psychology & Health and Health Psychology Review for relevant papers to answer these questions. Kaptein uses the example of primary prevention and eating behaviour to discuss the principle of autonomy, the example of theory based research for the principle of beneficence, the example of screening programmes for the principle of non-maleficence and the example of outcomes for the principle of justice. Kaptein concludes by highlighting the need to add more ethical criteria in health psychology.

Conclusion

Ethical considerations are unavoidable when conducting research in and practising health psychology. Even when we claim that we do not do ethics, our practices are informed by ethical principles and the more we are aware about them, the better we can align our practices towards ethical research. We are always left with the problem of values. The current debate about the use of facebook data in a prestigious American journal (see Kramer, Guillory & Hancock, 2014) and the subsequent 'editorial letter of concern' (see Verma, 2014) highlights the problem of when ethical procedures need to be adhered to and by whom.

All authors in this issue provide a very useful insight on what needs to be considered and

developed further in the area of ethics and health psychology and they provide practical recommendations. These are relevant to methodology and interpretation of research findings, participants' choice within the market-based healthcare system, tailored information for research participants and meaning of the research outcomes. These recommendations seem to be timely and important for the current attempts to develop a common scientific language and apply health psychology research above and beyond any unethical systems.

References

Field , A.P. (2014). Dread returns to Mega-Silly One. *Health Psychology Review*, doi:10.1080/17437199.2013.879198

Fotaki, M. (2014). Ethical implications of introducing patients' choice in the National Health System in England. *The European Health Psychologist, 16*(3), 95-100.

Greehalgh, T., Howick, J., & Maskery, N. (2014). Evidence based medicine: a movement in crisis? *BMJ, 348*(g3725). doi: 10.1136/bmj.g3725.

Kaptein, A. (2014). Ethics in health psychology-some remarks from an outsider. *The European Health Psychologist, 16*(3), 90-94.

Kramer, A.D.I, Guillory, J.E., & Hancock, J.T. (2014) Experimental evidence of massive-scale emotional contagion through social networks. *Proceedings of the National Academy of Sciences of the United States of America, 111*, 8788–8790. doi: 10.1073/pnas.1320040111

Schofield, B. (2014). Informed consent in research. *The European Health Psychologist, 16*(3), 101-106.

Taut, D. (2014). Is it ethical to advise people to "fight" cancer? *The European Health Psychologist, 16*(3), 107-111.

Verma, I. N., (2014). *Editorial expression of concern*. http://www.pnas.org/content/early/2014/07/02/1412469111.full.pdf

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original article

Ethics in Health Psychology

Some remarks from an outsider

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I am not an expert in ethics. I like being an explorer so that's why I agreed to try and write a few words about ethics in health psychology research and applied work in that area. Combining two disciplines of research areas quite often does result in finding unexpected results.

The APA, BPS, BHPS and comparable professional organizations for (health) psychologists provide researchers with rules and regulations regarding ethics about research and clinical work. I applaud the existence and enforcement of those regulations. However, my contribution is not about these issues, it is about exploring health psychology research in the context of the principles of medical ethics. The principles of medical ethics, if applied appropriately, should prompt us to conduct a deeper examination of the values and purpose of our research.

Most researchers consider Committees on (Medical) Ethics a pain in the neck. The bureaucracy involved with obtaining approval from those committees usually is quite exhaustive and time-consuming. We would expect that journals publishing research about human behavior would adhere to such criteria, with the editors playing a gatekeeper role. This, however, turns out to be not the case – at all. Too often researchers in the medical domain have failed to adhere to principles of medical ethics, with sometimes horrifying consequences (see for example Jones, 1981, on the Tuskegee experiment, where poor African Americans were research participants [victims is a better word] in whom effective medical treatment for syphilis was withheld on purpose by MDs who were fully aware of the horrific consequences). Obviously, health psychologists do not intentionally expose humans to contagious disease or to interventions that cause major physical damage. Nevertheless, studies in health psychology do run the risk of being unethical for other reasons – reasons germane to the nature of health psychology.

The four basic principles of medical ethics are:

Autonomy: people have a right to control what happens to their bodies.

Beneficence: all healthcare providers must strive to improve their patient's health, to do the most good for the patient in every situation.

Nonmaleficence: "First, do no harm" is the bedrock of medical ethics. In every situation, healthcare providers should avoid causing harm to their patients.

Justice: one should try to be as fair as possible when offering treatments to patients and allocating scarce medical resources (Runzheimer, & Larson, 2010).

Let's examine to what degree these four basic principles of medical ethics are adhered to by health psychologists in their work, and discuss some of the implications of the findings.

Method

I checked *Psychology & Health* and *Health Psychology Review*, starting with the most recent issues, for papers that in my view illustrate to

what degree health psychologists adhere to these four principles. The choice is nonrandom: I did my best to identify papers that seem to give rise to at least some questions regarding their ethics. I do not intend to criticize the authors or the papers. I merely wanted to see whether the four principles of medical ethics would give some insight into ethical issues in research done in health psychology.

I identified four examples, covering the four medical ethics principles in order to see whether they might illustrate problematic (medical) ethical issues in the research reported in the selected papers.

Results

The figure below attempts to illustrate the results of my method.

Principle	Health Psychology Equivalent	Paper
Autonomy	Primary prevention	Kaplan (1990; 2000)
Beneficence	Health psychology models	Ogden (2003; in press)
Nonmaleficence	Screening	Holtzman & Marteau (2000)
Justice	Outcomes	Kaptein (2011)

Figure 1. Four principles of medical ethics, proposed equivalents in health psychology research, and four commentaries on the principles of (medical) ethics as applied in health psychology

The first principle of medical ethics, autonomy, may be conceptualized as encompassing primary prevention in health psychology terms. Kaplan (2000) eloquently analyzed why **primary prevention** is in the behavioural – and not the medical - domain. "Primary prevention is usually based on a behavioral rather than a disease model. Diagnosis plays a lesser role because there is no disease to diagnose. Intervention is typical behavioral … interventions might also include public policy change …" (p. 383). I agree with Kaplan here. Nevertheless, research by health psychologists in the area of primary prevention may be tricky. The paper by Lange et al. (2013) in Psychology & Health may serve as an example of a health psychology study where a primary prevention view was applied to eating behaviour. Intentions and self-reported behaviour were studied. Health psychologists have been and still are involved in work on encouraging eating more healthily. Huge amounts of money have been spent on efforts to reduce the eating of high cholesterol food stuff, encouraging to eat more fatty fish – all sold under the guise of preventing cardiovascular diseases. The point is not that eating healthy may prevent illness. The point is that health psychologists may be acting unethically by joining the bandwagon of medical fashions.

The second principle of medical ethics, beneficence, can be linked with a highly popular activity in health psychology circles, i.e., developing and testing **theoretical models**. Does applying a theoretical model such as the Theory of Planned Behaviour (TPB) benefit the respondents in research about, for instance, sexual behaviour, problematic alcohol use, or living with psoriasis? Given the heated debates in Psychology & Health in recent issues about the value of this theoretical model and others, we adopt an arrogant stance: "we told you so

earlier" (Kaptein, 2011; Ogden, 2003, in press). Again, science by definition is closely associated with developing, testing, rejecting, revising, etc. theoretical models (Schwarzer, in press). My point is that most theoretical models in health psychology do not seem based in clinical reality and do not seem to benefit the human race considerably. Ogden defined them as 'uninteresting, blatantly obvious and ridiculous' (Ogden, 2003; Ogden, in press); I had the guts to conclude that it is time for health psychology 'to pick up the pieces and go home' (Kaptein, 2011).

Third, nonmaleficence ['primum non nocere' – first, do no harm], seems relevant in the context of **screening**. I maintain that screening is a sin. This goes for all types of cancer and for many other (risks for) diseases. Marteau is a leading author in the health psychology area who critically analyses thinking behind various screening programmes (Holtzman, & Marteau, 2000). Screening for breast cancer most likely does not lead to reductions of morbidity and mortality (Biller-Adorno, & Jüni, 2014). Attempts by health psychologists to try and increase attendance at breast cancer screening, therefore, quite likely are unethical (Brown, Gibney, & Tarling, 2013). Screening for colorectal carcinoma most likely does more harm than good, making efforts by health psychologists to try and motivate healthy persons to attend screening unethical (Manne et al., 2013). Attempts to introduce screening for lung cancer are wonderful for providing work for the medical system. It will only increase the length of suffering for identified patients.

The fourth potentially unethical principle is **outcomes**. "Behavior as the central outcome in health care" by Bob Kaplan (1990) belongs to one of my favorite papers. He points out how physiological measures (blood pressure, pulmonary function, etc.) are only intermediate outcomes in health care. In a recent exciting paper, 'health' was defined as 'the ability to adapt and to self manage' (Huber et al., 2011, p. 237). Many health psychologists, however, appear to be happy with outcome measures in their research that can be characterized as unreliable and meaningless (e.g., Coyne, & van Sonderen, 2011). Too many studies still assess self-reported intentions to perform assumed healthy behaviours in studies with psychology students or university staff as respondents (e.g., Berli et al., 2014; Caudroit et al., 2014). Medical ethics committees that evaluate research proposals about patients will not give their permission if the study would focus on outcomes, judged by experts to be meaningless. Comparable committees in social sciences schools should do the same: withhold their permission if the researchers propose studies with meaningless outcomes such as 'intentions to be physically active' or 'intention to use a condom', or questionnaires with questionable psychometric characteristics, or first year psychology students as respondents. Editors of journals in the area of health psychology who will take a comparable position and reject manuscripts that suffer these fatal flaws would be my heroes.

Discussion

Applying the four principles of medical ethics to health psychology research and applied work in the area seems an interesting undertaking – if one shares my critical views about a substantial part of research in health psychology. This paper is an attempt to extend principles laid down by professional societies in (health) psychology by pointing out that additional criteria of ethics may be relevant in health psychology. Adopting these views might even imply checking whether research proposals adhere to these principles – with the chance of them being rejected because

they are "ridiculous, blatantly obvious, boring, or typical of 'pick up the pieces and go home' research" (Kaptein, 2011; Ogden, in press).

We limited our paper to a few key journals in health psychology. It is our impression that had we included journals from the social psychology area we would have had a field day (given also the extremely embarrassing and damaging examples of fraud in those circles). We leave this to future researchers.

As said in the Introduction, I am not an expert in ethics. I do hope, however, that this contribution will help stimulate debate about ethical and unethical research in health psychology.

References

Berli, C., Loretini, P., Radtke, T., Hornung, R., & Scholz, U. (2014). Predicting physical activity in adolescents: The role of compensatory health beliefs with the Health Action Process Approach. *Psychology & Health, 29*(4), 458 – 474. doi:10.1080/08870446.2013.865028

Biller-Andorno, N., & Jüni, P. (2014) Abolishing mammography screening programs? A view from the Swiss Medical Board. *New England Journal of Medicine, 370*, 1965 – 1967. doi:10.1056/NEJMp1401875

Brown, S. L., Gibney, T. M., & Tarling, R. (2013). Busy lifestyles and mammography screening: Time pressure and women's reattendance likelihood. *Psychology & Health, 28*(8), 928 – 938. doi:10.1080/08870446.2013.766734

Caudroit, J., Boiché, J., & Stephan, Y. (2014). The role of action and coping planning in the relationship between intention and physical activity: A moderated mediation analysis. *Psychology & Health, 29*(7), 768 – 780. doi:10.1080/08870446.2014.884223

Coyne, J. C., van Sonderen E. (2012). No further research needed: Abandoning the Hospital and Anxiety Depression Scale (HADS). *Journal of Psychosomatic Research, 72*(3), 173 – 174. doi:10.1016/j.jpsychores

Holtzman, N. A., & Marteau, T. M. (2000). Will genetics revolutionize medicine? *New England Journal of Medicine, 343*, 141 – 144. doi:10.1056/NEJM200007133430213

Huber, M., Knottnerus, J. A, Green, L., van der Horst, H., Jadad, A. R., Kromhout, D.,... Smid, H. (2011). How should we define health? *BMJ, 343*, 235 – 237. doi:10.1136/bmj.d4163

Jones, J. H. (1981). *Bad blood: The Tuskegee syphilis experiment*. London: Free Press.

Kaplan, R. M. (1990). Behavior as the central outcome in health care. *American Psychologist, 45*(11), 1211 – 1220. doi:10.1037/0003-066X.45.11.1211

Kaplan, R. M. (2000). Two pathways to prevention. *American Psychologist, 55*(4), 382 – 396. doi:10.1037/0003-066X.55.4.382

Kaptein, A. A. (2011). Pick up the pieces and go home – on the demise of health psychology. *Health Psychology Review, 5*(1), 39 – 47. doi:10.1080/17437199.2010.520114

Lange, D., Richert, J., Koring, M., Knoll, N., Schwarzer, R., & Lippke, S. (2013). Self-regulation prompts can increase fruit consumption: A one-hour randomised controlled online trial. *Psychology & Health, 28*(5), 535 – 545. doi:10.1080/08870446.2012.751107

Manne, S. L., Kashy, D. A., Weinberg, D. S., Boscarino, J. A., Bowen, D. J., & Worhach, S. (2013). A pilot evaluation of the efficacy of a couple-tailored print intervention on colorectal cancer screening practices among non-adherent couples. *Psychology & Health, 28*(9), 1046 – 1065. doi:10.1080/08870446.2013.781601

Ogden, J. (2003). Some problems with social cognition models: A pragmatic and conceptual analysis. *Health Psychology, 22*(4), 424 – 428. doi:10.1037/0278-6133.22.4.424

Ogden, J. (2014). Time to retire the theory of

planned behaviour? One of us will have to go! A commentary on Sniehotta, Presseau and Araújo-Soares. *Health Psychology Review*. Advance online publication. doi:10.1080/17437199.2014.898679

Runzheimer, J., & Larsen, L.J. (2010). *Basic principles of medical ethics*. Chichester: Wiley.

Schwarzer, R. (2014). Some retirees remain active: A commentary on Sniehotta, Presseau and Araújo-Soares. *Health Psychology Review*. Advance online publication. doi:10.1080/17437199.2014.898407

Sniehotta, F.F., Presseau, J., & Araújo-Soares, V. (2014). Time to retire the theory of planned behaviour. *Health Psychology Review, 8*(1), 1 – 7. doi:10.1080/17437199.2013.869710

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original article

Ethical implications of introducing patient choice in the National Health Service in England

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Patient and user choice is at the forefront of the debate about the future direction of the provision of health and other public services in many industrialised countries (Beusekom Tonshoff, de Vries, Spreng, & Keeler, 2004; Williams & Rossiter, 2004). Specifically, in publicly funded and provided health care systems, where choice has been, or is perceived to have been historically lacking, increasing it has become a key policy objective (Ashton, Mays, & Devlin, 2005; Vrangbæk, Robertson, Winblad, van de Bovenkamp, & Dixon, 2012). Promoting market-based individual patient choice, first introduced in the 1990s, has now become a standard health policy objective in the National Health Service (the NHS) in England. The passing of the Health and Social Care Act 2012 (Department of Health, 2012), means that this trend is set to continue.

The idea of patient choice in health services is founded on two general assumptions: one is that it will aid competitive markets in their tasks to improve the efficiency of providers as well as improve quality; the other is that the exercise of choice is an important good in itself for patients. But the assumptions on which the policy rests have been found wanting (Fotaki et al., 2006; Greener, 2008). Their applicability is either severely limited or invalid when applied to health care, for both theoretical and empirical reasons. The paper discusses these limitations and then explores the ethical implications of introducing market-based patient choice in health care.

The limitations of the market-type patient choice in health care

First, the necessary theoretical pre-conditions rarely apply in health care since health is not a commodity that can be easily sold and exchanged. Health care markets are rarely competitive, and patients often lack information needed to make choices although patients with long term conditions may be more able to make informed choices (Singh & Ham, 2006). The narrative of knowledgeable users of public services exercising their preferences via acts of consumption overlooks something that is actually central to health care choice in real life: the patient's need for trust-based relationships with care providers (Taylor-Gooby, 1999). Precisely because patients lack the information needed to make informed choices about their care, they need medical professionals they can trust; this overrides their desire to 'shop around' (Fotaki, in press). Even in material markets people are seldom rational choosers and least of all in relation to health services (Ferraro, Shiv, & Bettman, 2005). Individuals do not always choose what is in their best interest even if they are able to identify it (Hoggett, 2001) – allowing them to make decisions which are acceptable to them but which may not be entirely rational - a reality that economists have now come to acknowledge (Thaler & Sunstein, 2008). For patients, the severity of their medical condition amplifies the bias in processing information that the human mind is prone to even further (Kahneman & Tversky, 1979).

Second, choice means different things to

different or the same people at various points in time because users of services share multiple identities as citizens, family and community members, members of religions, and much more. Patients' ability, and even their willingness to make choices, is influenced by their beliefs, cultural values and expectations as well as their life circumstances, personal characteristics and their experiences of health care services (Fotaki, et al., 2008). Put differently, the individual choices we make are socially constructed (Pescosolido, 1992).

Third, patients do not seem strongly attracted to the idea of consumerist market choice in health care. Thus a recent review of choice in public services in the UK found that only 35 percent of patients exercised choice of hospitals (Boyle, 2013). What mattered more to patients was obtaining information about their treatment (Picker Institute Europe, 2007). Although generally positive about having choices, the most important aspects from patients' points of view concerned their involvement in treatments rather than hospitals or providers (Coulter, 2010). In reality, patients were able to choose between hospitals and appointment times rather than primary doctors, hospital consultants and treatments. The ability of a patient-consumer to assess the quality of medical services received is for many types of treatment is thus limited to such relatively peripheral issues as waiting time, comfort of waiting rooms and wards, and friendliness of staff, which they can use as a proxy for information to exercise choice. Fourth, introducing consumer choice might alter the meaning of trust in different situations in health care and damage the legitimacy of the service through eroding public's trust in the system such as the NHS (Taylor-Gooby & Wallace, 2009).

Overall, personalised choices are in conflict with the collective goals of public health systems (equity and efficiency) as more resources are likely to be needed to meet individualized patients' wants at the expense of equal availability of services to all (Oliver & Evans, 2005). This can happen either because some patients receive preferential access and treatment under certain schemes (as was the case under the internal market in the UK with the patients of GP fund-holders obtaining a preferential access to hospitals with shorter waiting times) (Mannion, 2005) or because physicians are likely to modify their behaviour in order to fit the market, which could benefit some patients more than others. Such outcomes are incompatible with the goals of universal health care systems.

Last but not least, introducing market incentives of competition and choice is likely to have important implications for not only changing the ethos of public services but also for ethics of care underpinning patient and doctor/nurse interaction. The latter might be the effect of moderating health professional behaviours after introducing markets incentives when they are expected to respond and report on financial and other targets rather than devote time and energy to provide care services to the patients. The widely discussed Francis Report (2013, p. 4) caused alarm amongst regulators and central government alike, identifying "the need to change a culture focused on doing the system's business - not that of patients". A key lesson and ethical implications from Staffordshire hospital's tragic neglect of patients care are discussed next.

The ethical implications of introducing markets in health care: The case of the Mid Staffordshire NHS Trust

The Mid Staffordshire NHS Trust failures in

rudimentary aspects of care and the widespread and systemic patient abuse taking place in this instance (involving leaving dying patients hungry, soiled and in pain for hours see –Donnelly, 2013) is extreme but not unusual. While the hospital's management embarked on cutting costs in this specific case, the staffing requirements needed to provide adequate patient care, and arguably the patients themselves, were ultimately seen as 'getting in the way' of achieving the hospital's strategic goal. This has also been shown to be a direct result of giving priority to demonstrating 'financial health' which was a necessary precondition for achieving foundation trust status by the hospital. The Francis Report provides a damning indictment of such an approach: 'While the system as a whole appeared to pay lip service to the need not to compromise services and their quality, it is remarkable how little attention was paid to the potential impact of proposed savings on quality and safety' (Francis Report, 2013, p. 45).

But how could managers or even the frontline staff distance themselves from the obvious task of providing care to the point of criminal negligence? Though moral responsibility for any action rests ultimately with the individual, the widespread failing in care standards cannot be simply attributed to callous and uncaring staff. In order to understand why this happens we must move beyond simplistic frames taken from economics pointing at self-interest as a single key driver of human behavior. Some recent research in clinical psychology suggests how almost anyone might engage in unethical behaviour, thanks to a complicated and socially reinforced mix of organisational and individual factors having to do with mental framing, perceptions and unconscious motives (Bazerman & Banaji, 2004).

Organisational research confirms that when explicit targets are coupled with a strong incentives (and/or disincentives), people will strive to meet them often at the expense of a common sense (Schwartz, 1987). This could sometimes even lead to them violating socially accepted norms (Fotaki & Hyde, 2014) as they are working towards meeting impersonal organizational targets (Ferlie, McGivern, & FitzGerald, 2012). Indeed, the findings from the Francis Report confirm the absence of 'a sufficient sense of collective responsibility or engagement for ensuring that quality care was delivered at every level' (Francis Report, 2013, p.44). Managers and organisations are critical to the creation of an ethical environment but the overall policy framework in which they operate is even more important. Therefore, providing adequate training proposed by the UK government on its own is unlikely to be an effective way of ensuring that nurses and doctors treat their patients with compassion given that they will be introduced at a time when new competitive pressures are being introduced to the health service. The evidence from the USA suggests that combining marketisation with cost-saving mechanisms has reduced trust in the health system and physicians (Rhodes and Strain, 2000; Mechanic, 1996), who report that they are less able to either avoid conflicts of interest or put the best interests of patients first (Feldman, Novack, & Gracely, 1998). Although probably less pronounced than in the USA, a decrease of patient trust in response to physicians modifying their behaviours to fit the market has been observed in Sweden (Bergmark, 2008) and the Netherlands (Dwarswaard, Hilhorst, & Trappenburg, 2011) following the introduction of competition and choice. Codes of ethics along with the lengthy socialisation process into the norms and values of the profession might be difficult to adhere to when resources are squeezed and the norms and values are altered.

Conclusion: Market choice and the logic of care

Consumerist choice, aiming to substitute for interdependency and care in health services is far removed from the lived materiality of bodies and the logic of care. In the absence of a caring professional, choice and information are utterly ineffective to the point of being useless. This is not to say that patients are not interested in receiving relevant and usable information about their treatment, but to stress the role of relationality in care situations. Although offering patients' choice appears to be what patients want however, but this does not necessarily translate into desire for a consumerist system but rather a partnership with their clinician where the knowledge of the expert is utilised by the patient. Derived from early 20th century theories of consumer demand and neoclassic economics, the prevailing logic of choice assumes that patients act as calculating and rational utility-maximisers even though people are known to not generally behave as economic models predict. When making complex health decisions, patients rely on their intuition and emotions involving the avoidance of regret as well as trusted networks, rather than objective, impersonal data (Ryan, 1994).

Patients' need for relational aspects of care (Mol, 2008), that do not easily fit with consumerist ethos of the market choice, is disregarded in recent reforms which promote it. Although it is possible to treat people who seek professional help as customers this is incompatible with ways of thinking and acting that are crucial to health care. Good care grows out of collaborative and continuing attempts to attune professional knowledge and technologies to diseased bodies and complex lives (Mol, 2008). Framing the issue of choice in the context of market competition roots it in old-school neo-classical economics and involves a significant narrowing of the concept of choice, and of the users of health services as rational 'choosers' exercising their preferences. Choice and independence are indeed powerful concepts, but interdependency is an essential part of social life and never more so than in the times of illness and vulnerability.

References

Ashton, T., Mays, N. & Devlin N. (2005). Continuity through change: the rhetoric and reality of health reform in New Zealand. *Social Science & Medicine, 61*(2), 253-262. doi:10.1016/j.socscimed.2004.07.004

Bazerman, M. & Banaji, M. (2004). The social psychology of ordinary ethical failures. *Social Justice Research, 17*(2), 111-115. doi:10.1023/B:SORE.0000027544.56030.04

Bergmark, A. (2008). Market reforms in Swedish health care: normative reorientation and welfare state sustainability. *Journal of Medicine and Philosophy, 33*(3), 241-261. doi:10.1093/jmp/jhn010

Beusekom, I., Tonshoff, S., de Vries, H., Spreng, C., & Keeler, E. B. (2004). *Possibility or utopia? Consumer choice in health care: A literature review*. Santa Monica: RAND Corporation.

Boyle, D. (2013). *The barriers to choice review. How are people using choice in public services?* London: Cabinet Office.

Coulter, A. (2010). Do patients want choice and does it work? *British Medical Journal, 341*, 972–975. doi:10.1136/bmj.c4989

Department of Health. (2012). *Health and Social Care Act*. London: Department of Health.

Donnelly, L. (2013, January 6). *Stafford Hospital: the scandal that shamed the NHS*. Retrieved from: http://www.telegraph.co.uk/health/heal-our-hospitals/9782562/Stafford-Hospital-the-

scandal-that-shamed-the-NHS.html

Dwarswaard, J., Hilhorst, M., & Trappenburg, M. (2011). The doctor and the market: About the influence of market reforms on the professional medical ethics of surgeons and general practitioners in the Netherlands. *Health Care Analysis, 19*(4), 388–402. doi:10.1007/s10728-011-0166-z

Feldman, D. S., Novack, D. H., & Gracely, E. (1998). Effects of managed care on physician-patient relationships, quality of care, and the ethical practice of medicinea physician survey. *Archives of Internal Medicine, 158*(15), 1626-1632. doi:10.1001/archinte.158.15.1626

Ferlie, E., McGivern, G., & FitzGerald, L. (2012). A new mode of organizing in health care? Governmentality and managed networks in cancer services in England. *Social Science & Medicine, 74*(3), 340-347. doi:10.1016/j.socscimed.2011.03.021

Ferraro, R., Shiv, B., & Bettman, J. R. (2005). Let us eat and drink, for tomorrow we shall die: Effects of mortality salience and self-esteem on self-regulation in consumer choice. *Journal of Consumer Research, 32*(1), 65-75.

Fotaki, M. (in press). Can consumer choice replace trust in the National Health Service in England? Towards developing an affective psychosocial conception of trust in health care. *Sociology of Health & Illness, 15*(1).

Fotaki, M., & Hyde, P. (2014). Organizational blind spots: Splitting, blame and idealization in the National Health Service. *Human Relations*. Advance online publication. doi:10.1177/0018726714530012

Fotaki, M., Boyd, A., Smith, L., McDonald, R., Roland, M., Sheaff, R., … Elwyn, G. (2006). *Patient choice and the organisation and delivery of health services: scoping review. A report to the NHS Service Delivery and Organisation (NCCSDO)*. London: SDO.

Fotaki, M., Roland, M., Boyd, A., McDonald, R., Scheaff, R., & Smith, L. (2008). What benefits will choice bring to patients? Literature review and assessment of implications. *Journal of Health Services Research and Policy, 13*(3), 178–184. doi:10.1258/jhsrp.2008.007163

Francis, R. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (Ed)*. London: The Stationery Office.

Greener, I. (2009). Towards a history of choice in UK health policy. *Sociology of Health & Illness, 31*(3), 309-324. doi:10.1111/j.1467-9566.2008.01135.x

Hoggett, P. (2001). Agency, rationality and social policy. *Journal of Social Policy, 30*(1), 37-56.

Kahneman, D., & Tversky, A. (1979). Prospect theory: An analysis of decision under risk. *Econometrica, 47*(2), 263–292.

Mannion, R. (2005). *Practice – based budgeting: Lessons from the past; prospects for the future. Report to the Department of Health*. York: Centre for Health Economics, University of York.

Mechanic, D. (1996). Changing medical organisations and the erosion of trust. *Milbank Quarterly, 74*(2), 171-189.

Mol, A. (2008). *Choice. The Logic of Care*. London: Routledge.

Oliver, A., & Evans, J. G. (2005). The paradox of promoting choice in a collectivist system. *Journal of Medical Ethics, 31*(4), 187. doi:10.1136/jme.2005.011809

Pescosolido, B. A. (1992). Beyond rational choice – the social dynamics of how people seek help. *American Journal of Sociology, 97*(4), 1096–1138. doi:10.1086/229863

Picker Institute Europe. (2007). *The 2006 Inpatients Importance Study*. Oxford: Picker Institute Europe.

Rhodes, R., & Strain, J. J. (2000). Trust and transforming medical institutions. *Cambridge Quarterly of Healthcare Ethics, 9*(2), 205–217.

Ryan, M. (1994). Agency in health care: Lessons for economists from sociologists. *American*

Journal of Economics and Sociology, 53(2), 207–217. doi: 10.1111/j.1536-7150.1994.tb02588.x

Schwartz, H. (1987). Anti-social actions of committed organizational participants: An existential psychoanalytic perspective. *Organization Studies, 8*(4), 327-340. doi: 10.1177/017084068700800403

Singh, D., & Ham, C. (2006). *Improving care for patients with chronic conditions. A review of UK and International Frameworks.* Birmingham: HSMC University of Birmingham.

Taylor-Gooby, P. (1999). Markets and motives trust and egoism in welfare markets. *Journal of Social Policy, 28*(1), 97-114.

Taylor-Gooby, P., & Wallace, A. (2009) Public values and public trust: Responses to welfare state reform in the UK. *Journal of Social Policy, 38*(3), 401–419.

Thaler, R. H., & Sunstein, C. R. (2008). *Nudge: Improving decisions about health, wealth, and happiness*. New Haven, CT: Yale University Press.

Vrangbaek, K., Robertson, R., Winblad, U., Van de Bovenkamp, H., & Dixon, A. (2012). Choice policies in Northern European health systems. *Health Economics, Policy and Law, 7*(1), 47-71. doi:10.1017/S1744133111000302

Williams, J., & Rossiter, A. (2004). *Choice: the evidence. The operation of choice systems in practice: national and international evidence.* London: The Social Market Foundation.

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original article

Informed consent in research

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The developments in the protection of human participants in research evolved following the Nuremberg trial of Nazi doctors leading to the Nuremberg Code (Annas & Gordin, 1992; European Commission, 2010; Faden, 1989), which highlighted the following safeguards and is the basis for subsequent ethical codes and guidelines internationally;

- *The voluntary consent of the human subject is absolutely essential*
- *Favorable risk-to-benefit analysis*
- *The right to withdraw without repercussions*

Informed consent has been described as 'a precondition for autonomous decision-making' (Biggg, 2010). The social values most notably stated as being promoted by the requirement of informed consent are autonomy and trust (O'Neill, 2002). However there is no statute based law of consent in the United Kingdom (UK). Practical guidance in terms of the practical operation of consent is led by guidance from professional organisations for healthcare professionals. Importantly, consent is commonly regarded as the cornerstone of medical law and ethics (Agich, 1998).

The benefits of informed consent in relation to research on human participants can be seen as respect for participants, engaging the participants with the study and enhancing the researcher-participant relationship, which may reduce discontent and litigation. However a universal insistence on consent can introduce selection bias (a systematic error in a study based on the processes used to select the study participants) and participation bias (caused by differences between participants and non-participants), which will limit recruitment of study participants and may affect the generalisability of the study findings by reducing the statistical power of the findings (Kho, Duffett, Willison, Cook, & Brouwers, 2009). The requirement, may overburden limited resources in terms of time and financial costs.

Informed consent in the context of research on human participants evolved in a different but parallel sphere to informed consent to medical treatment. Before the contemporary era, many people were used in research not only without their knowledge but also, sometimes against their expressly stated wishes (Mallardi, 2005). Two central aspects play a crucial ethical role in the recruitment of participants to research studies. These are that the consent to participate is fully informed and freely given. The informed consent process has been seen as necessary both to protect individuals from harm, safe-guarding their well being, and to protect the basis of autonomy as a right in itself by allowing potential participants an autonomous choice (Ursin, 2009).

Elements of informed consent

For consent to be valid the process of information giving in itself is not enough. The element of understanding is the basis of this validation. The information given needs to be

adequate for the research participant. It must include the purpose of the study, any significant risks to the participant and details of financial aspects of the study that could highlight potential conflicts of interest. Information is imparted by speaking with the participants as well as using information sheets. Literacy and language can be major barriers in understanding for potential participants. According to Flory, Wendler and Emanuel generally 75% of participants understand the purpose of a study (2007). Appelbaum described the therapeutic misconception leading research participants to believe their participation in the study will benefit them in the same way as clinical care (Appelbaum, Lidz, & Grisso, 2004). Attention must be paid to ensure potential participants understand the underlying reasons for research. The amount of information imparted in the consenting process may lead to information overload, which will in turn affect understanding. The type of research study will dictate what, how and how much information should be provided in the consenting process. But it is important to note that complete understanding by the participant cannot be guaranteed. However it must be of an adequate level for the participant to make a decision.

Informed consent must also be given freely. Voluntariness demonstrates the autonomous participant has not been controlled in any way into agreeing to consent. It has been recognised that decisions are rarely made free from external control (Kottow, 2004). This notion is well defined by Faden and Beauchamp (Faden, & Bauchamp, 1989). They recognise that not all external controls and influences are controlling. Accordingly they state that coercion is always fully controlling and thus is not compatible with informed consent, whereas persuasion, not being controlling is compatible with informed consent. It is important that a power imbalance of researcher and participant does not play a role in manipulating the voluntary nature of the informed consent process. Furthermore the study information sheet must make it clear that participants do not have to take part if they do not wish to do so and that they can withdraw from the study at any time without that decision affecting their usual care. Studies have revealed that this element of the consent process is poorly understood and undermines the voluntariness of research participants as they may continue to participate in a study even after they decide they would rather no longer be part of the study (Flory & Wendler, 2007).

The final required element is competence. Competence is defined as a participant having decision-making capacity to utilise the information they have been given to make a free and voluntary decision. In those participants identified as lacking capacity and children generally under the age of 16, proxy consent may be sought. In healthcare settings, the healthcare team will have had time to assess competence in the course of their usual clinical care. This is a more problematic assessment in the research environment if participants are recruited without the involvement of usual healthcare providers. It is also the case that potential participants may not be able to exercise their decision-making capacity whilst in, for example, prison. The setting needs careful consideration when seeking informed consent.

The role of Research Ethics Committees

In medical research, Research Ethics Committees have to approve research studies and the informed consent process for each study is assessed during this process. There appears to

be a lack of agreement as to how populations are to be assessed for understanding. Informed consent is being judged presently without an assessment of its success. Since the first Research Ethics Committee was formed in the United Kingdom in 1966 it has become a function of the committee to make assessments of the nature and adequacy of the consent strategies for each of the research studies reviewed (Gelling, 1999). Consent is usually obtained with the use of a consent form, which is signed by the research participant before their participation in research. In a review of the evolution of consent forms for research over a 25 year period, Albala et al. reviewed research protocols and consent forms reviewed by an Institutional Review Board in a major academic medical centre (Albala, Doyle, & Appaelbaum, 2010). They concluded that the length of consent forms have increased 'linearly by an average of 1.5 pages per decade.' The increase in length of consent forms may be problematic if the three stated elements of informed consent are to be satisfied.

Consent requirements: an ongoing debate

Within the realm of medical research, the different strategies of consent are the basis of much of the ongoing debate on informed consent. The differences are essentially obtaining individual informed consent or not obtaining individual informed consent. In using anonymised data, consent is not a legal requirement. This is based on the current interpretation of the legal framework. But in needing to access identifiable data consent is required.

Consent requirements are different in the case of emergencies and in research on vulnerable groups. In undertaking research in the emergency setting where the participants are unable to provide consent, an ethics review body will need to have approved the study protocol. In undertaking research on vulnerable adults alternatives to the standard consent process are considered appropriate. These are accepting consent from a proxy to make the decision on their behalf or to rely on an advance statement if one has been prepared (General Medical Council, 2013). Children are commonly viewed as a vulnerable group in relation to research. Usually a parent provides consent on behalf of the child, although obtaining the assent of the child as well acts as another means of protecting the interests of the child and it is encouraged. The best interest standard is usually upheld when making decisions on behalf of a child (Shah, 2013).

Legal perspectives

The legal significance of informed consent derives from two main areas of law - negligence and assault and battery. Despite the acceptance in both ethics and law, that a person should have choice about their participation in research there is no "…. specific statute-based law of consent in the United Kingdom, and the concept has developed through common law judgments. Similarly, there is no UK case law pertaining explicitly to consent in research." (Biggs, 2010). The requirements of the information expected to have been provided, to a research participant are different to that which is required to be given to a patient in order to obtain consent. This information element is different as potential participants need to be aware of their freedom to withdraw from a study at any time and that the research may not directly benefit them. Compounding this issue is the element of data as gathered in the research process and its

use and protection as a result of participation in a study.

The decision whether or not to participate in research has become a fundamental right in English medical law. In her book exploring the relationship between law and ethics, Hazel Biggs notes;

> *"Broadly speaking, obtaining consent from a research participant authorises a clinician or researcher to have physical contact with the participant. It also protects the rights of participants to exercise their own autonomy and retain control over what happens to them. …. More generally, legal authorisation is required for any intervention involving interference with the physical integrity of the body, its tissue and fluids, or access to personal data and records."*

In the absence of a legal right to privacy until the 1990s, researchers were encouraged to undertake research using patient information as a professional ethical duty without an emphasis on obtaining informed consent or approval from Research Ethics Committees (Foster, 2001). The introduction of the Data Protection Act 1998 and a social setting focusing on patient-centered health care altered this research backdrop. This new legal framework has been interpreted in the context of 'consent or anonymise' in which obtaining individual consent is held to be the only ethically appropriate way of justifying the use of identifiable data (and where annonymised data has had the identifiable data removed from the data of interest).

The most important laws governing medical research using personal data in the UK include:

- *Data Protection Act 1998*
- *Common law of confidentiality*
- *Human Rights Act 1998*
- *Section 60 of the Health & Social Care Act 2001*

Individual consent and the interests of society

There is a debate surrounding the abandonment of informed consent in the governance of certain new research technologies. In the case of large databases, bioethicists and policymakers are considering the relevance and importance of obtaining individual narrow informed consent (Rommetveit, 2011). In bioethics the tension has always been between common good and individual autonomy. This has been founded on the need to protect the privacy of individuals versus the public interest. The liberal framework, which protects individuals and places autonomy at the core of the need for informed consent, is being tugged at by a communitarian 'turn' in bioethics. This term is defined by Ruth Chadwick as a "… shift in bioethics over the last decade or so, involving greater emphasis on principles of solidarity, equity and public good, as opposed to the prominence of autonomy-based arguments." (Chadwick, 2011).

In undertaking an exploration of the ethical and societal principles of the requirement for informed consent, stakeholders in the debate on informed consent were interviewed. The outcome of this study was that the presence of an improved level of background education in relation to research, trust in research practices and research participation combined with a societal shift to a more solidarity based model of society would provide the background seen as necessary for different consent strategies to be acceptable in undertaking research. A societal

shift to a more socially collective model of citizenship would be required for consent strategies to become less prescriptive as compared to individual opt-in strategies (Schofield, 2013).

Conclusion

Informed consent has become important due to historical developments, placing an emphasis on the individual. Alternative consent strategies based on a more societal model of citizenship combined with education and building up of trusting relationships will allow research to maximise its benefits whilst continuing to protect participants.

References

Agich, G. J. (1998). Human experimentation and clinical consent. In J. F. Monagle, & D. Thomasma (Eds), *Health care ethics: critical issues for the 21st century*. Gaithersburg, USA: Aspen Publications.

Albala, I., Doyle M., & Appelbaum P. S. (2010). The evolution of consent forms for research: A quarter century of changes. *IRB: Ethics and Human Research, 32*(3), 7-11.

Annas G. J., & Gordin M. A. (1992). *The Nazi doctors and the Nuremberg Code*. New York: Oxford University Press.

Applebaum, P. S., Lidz, C. W., & Grisso, T. (2004). Therapeutic misconception in clinical research: Frequency and risk factors. *IRB: Ethics Human Research, 26*(2), 1-8.

Biggs, H. (2010). *Healthcare research ethics and law. Regulation, review and responsibility*. Cavendish, New York: Routledge

Chadwick, R. (2011). The communitarian turn: Myth or reality? *Cambridge Quarterly of Healthcare Ethics, 20*(4), 546-553. doi:10.1017/S0963180111000284

European Commission (2010). *European textbook on ethics in research. European research area, Science in society*. Luxembourg: Publications Office of the European Union.

Faden, R. R., & Beauchamp, T. L. A. (1986). *History and theory of informed consent*. New York: Oxford University Press.

Faden, T. L. (1989). *A history and theory of informed consent*. Beauchamp Georgetown University: Oxford University Press.

Flory, J., Wendler, D., & Emanuel E. (2007). Informed consent for research. In R. E. Ashcroft, A. Dawson, H. Draper H., & J. R. McMillan (Eds), *Principles of health care ethics* (2nd ed). England: Wiley & Sons Ltd.

Foster, C. (2001). *The ethics of medical research on humans*. Cambridge: Cambridge University Press.

Gelling, L. (1999). Role of the research ethics committee. *Nurse Education Today, 19*(7), 564-569. doi:10.1054/nedt.1999.0349

General Medical Council (2013). *Good practice in research and consent to research*. Retrieved from: http://www.gmc.uk.org/static/documents/content/Good_practice_in_research_and_consent)

Kho, M. E., Duffett, M., Willison, D. J., Cook, D. J., & Brouwers M. C. (2009). Written informed consent and selection bias in observational studies using medical records: A systematic review. *BMJ, 338*(b866). doi:10.1136/bmj.b866

Kottow, M. (2004). The battering of informed consent. *Journal of Medical Ethics, 30*(6), 565-569. doi: 10.1136/jme.2003.002949

Mallardi, V. (2005). The origin of informed consent. *Acta Otorhinolaryngol Ital, 25*(5), 312-27.

O'Neill, O. (2002). *Autonomy and trust in bioethics. The Gifford Lectures*. Cambridge: Cambridge University Press.

Rommetveit, K. (2011). Tackling epistemological naivety: Large-scale information systems and

the complexities of the common good. *Cambridge Quarterly of Healthcare Ethics, 20*, 584-595. doi:10.1017/S0963180111000326

Schofield, B. (2013). *The ethical and societal implications of consent strategies in large-scale epidemiological studies* (Unpublished doctoral dissertation). University of Bristol, Bristol.

Shah, S. (2013). Does research with children violate the best interests standard? An empirical and conceptual analysis. *North-Western Journal of Law & Social Policy, 8*(2), 122-173.

Ursin, L. O. (2009). Personal autonomy and informed consent. *Medicine, Health Care and Philosophy, 12*(1), 17-24. doi:10.1007/s11019-008-9144-0

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original article

Is it ethical to advise people to "fight" cancer?

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In January 2014, in his article "Heroic Measures", the New York Times columnist, Bill Keller ignited a fervent debate over how much fight one is willing and should throw into a battle with cancer. The column explored the use of social media by Lisa Bonchek Adams- a women in her thirties suffering from terminal cancer and currently receiving palliative care. Adams chose to come public with detailed accounts of her treatments, her daily struggles and everyday challenges in thousands of tweets and dozens of blogposts. In a rather irreverent tone, Keller notes that "a rapt audience of several thousand follows her unsparing narrative of mastectomy, chemotherapy, radiation, biopsies and scans, pumps and drains and catheters, grueling drug trials and grim side effects, along with her posts on how to tell the children, potshots at the breast cancer lobby, poetry and resolute calls to 'persevere'." Whether Adams is a fighter, clinging to every straw of hope in prolonging her survival or whether the posts are her way of coming to terms with the implacable prognosis is one of the fervent debates around her case. Still, these controversies spurred by the comments of Keller bring to the forefront the pressing questions for psycho-oncology : "What does adaptive coping with cancer mean?", "Does personality in general and a fighting spirit in particular play a role in cancer progression and survival?" "Is promoting resilient psychological traits useful and can they increase the chances of longer survival?"

Attempts to address these questions can be traced back three decades when research on the effect of personality and coping grew in popularity. Thus, research showed that individuals with cancer who displayed a fighting spirit survived longer than those who displayed stoic, helpless or accepting attitudes (e.g. Greer, Morris, & Pettingale, 1979; Greer, Morris, Pettingale & Haybittle, 1990; Morris, Pettingale, & Haybittle, 1992; Pettingale, 1984; Tschuschke, Hertenstein, Arnold, Bunjes, Denzinger, & Kaechele, 2001). Fighting spirit describes the optimistic framing of cancer as a challenge rather than a burden and the determination of fighting and not allowing the disease to take control over the person's life (cf. Coyne & Tennen, 2010). Other traits associated with fighting spirit seemed to prolong survival. Denial - in the form of minimising the impact of cancer (Garssen, 2004, p. 328)- is associated with longer survival in metastatic melanoma and in metastatic breast cancer (Butow, Coates, & Dunn, 1999; Butow, Coates, & Dunn, 2000). Optimism – in opposition to pessimism- was proven as a helpful trait and was associated with longer survival in younger patients recieving palliative radiation treatment (Schulz, Bookwala, Knapp, Scheier, & Williamson, 1996). Even when fighting spirit did not seem to contribute to disease-free survival, its reversed counterparts, namely hopelesness and/or helplesness still played a negative role on survival rates (Watson, Homewood, Haviland, & Bliss, 2005). Finally, the work of Lydia Temoshok suggested that there might even be a "cancer-prone" (type C) personality, characterized by supression of emotions, self-sacrifice, self-blaming and need for cooperation, which would correlate with the

progression of different cancer types (Temoshok, 1987; Temoshok et al., 1985). Briefly, the figure of the succesful cancer survivor, as depicted in the psycho-oncological literature seemed to be a bold, outspoken and optimistic person, highly commited to defeating cancer.

However pervasive this steretypical cancer fighter might be, a closer analysis of research regarding the connection between positive personality traits and cancer reveals that such a relation is, in fact, shaky (Coyne & Tellen, 2010). A large systematic review found little convincing evidence that fighting spirit and helplesness/hopelessness would affect survival (Petticrew, Bell, & Hunter, 2002). Similar conclusions were reached by Nakaya et al. (2010) who in a large prospective cohort study showed virtually no association between personality traits (extraversion and neuroticism) and breast, corpus uteri, ovary or prostate cancers (N = 4631 with a follow-up span of 30 years). Watson, Haviland, Greer, Davidson, and Bliss (1999) failed to prove an effect of fighting spirit over survival, even though they did find a significant risk of death at 5 years in women scoring high on depression, helplessness and hopelessness scales. Finally, another longitudinal study found no evidence of an association between the incidence of breast cancer and personality traits such as anxiety, depression, optimism, or Type C personality traits (Bleiker, Hendriks, Otten, Verbeek, & van der Ploeg, 2008). What these studies have in common is their carefully planned prospective designs (or inclusion of longitudinal studies only- in Petticrew systematic review), recruitment of large samples and rigorous control of confounds.

Despite grey evidence, media and promoters of alternative medicine repeatedly stressed the importance of displaying a fighting attitude and other personality traits that would presumably increase the chances of a favorable prognosis. Suppose that these psychological traits predict not only psychological adjustment to cancer but also disease free survival. For cancer sufferers, not having them would mean a psychological incapacity of choosing the "right" over the "wrong" thinking at the expense of precious months or years of survival. Put another way, it would send the message that "brave and good people defeat cancer and that cowardly and undeserving people allow it to kill them" (Diamond, 1998, p. 52, cited in Coyne, Stefanek & Palmer, 2007). Also, the state-of-the-art in psycho-oncological research tells little as to whether these personality traits have cumulative effects in predicting cancer onset and progression. Also, it is not known if more protective traits can compensate for these 'bad' ones. Hence, after a detached, scientific analysis of the available data, what advice should we give to people facing the burden of cancer? Should they strive to keep an optimistic, fighting stamina? Is psychological adjustment a good-enough outcome or should they hope to also increase survival?

Although these questions bear considerable ethical dilemmas for professionals, the idea that the mind must have some control over the body is appealing. Not surprisingly, psychosocial interventions aimed at fostering adaptive attitudes that would, subsequently, increase psychological adjustment and (why not?) disease free survival were welcomed. Probably the most well-known and the most controversial study of the effects of psychotherapy on cancer survival rates suggests that group intervention aimed at exploring ways of coping with cancer and expressing feelings not only enhanced better psychological outcomes but also led to an average of 18 months longer survival in women receiving the intervention compared to the control group (Spiegel, Bloom, Kramer, Gottheil, 1989). Similar interventions seemed to increase survival at 6 years follow-up (Fawzy et al., 1993) and even at 10 years follow-up (Fawzy, Canada,

& Fawzy, 2003). Overall, according to Spiegel (2012), there were 8 controlled trials showing some survival benefits (besides psychological ones) of psychosocial interventions for different cancers and across cancer stages compared to 6 trials showing no benefits in terms of survival (3 of them did not showed improvement in psychological outcomes either). Still, positive findings largely come from underpowerd studies with poor adherence to the Consolidated Standards of Reporting Trials (CONSORT) standards, with no aprori asumptions regarding survival, no intention-to-treat analyses as well as some inappropriate data analyses, all of which inflated the probability of type 1 error (Coyne et al., 2007). Additionaly, claims regarding possible psychoneuroimmunological mechanisms through which psychosocial interventions would positively impact immunological functioning in cancer, were not investigated in these trials and therefore cannot be deemed plausable. On the contrary, more rigurously conducted reviews were less likely to find positive effects of psychosocial interventions on survival and suggest untested mechanisms of influence (Lepore & Coyne, 2006).

Putting it all together, the evidence regarding psychological traits associated with cancer and the presumable effects of psychosocial interventions on survival suggests a preccipitation of psycho-oncolgy to claim territories which are yet far from being conquered. This leaves room for the aggressive marketing of psychological ' recepies' to fight cancer in the ' right' way, in lay publications and in some scientific circles alike. The struggles of cancer patients to follow these scripts for success can be extremely burdening and may have paradoxical effects. Trying to be optimistic when one doesn't feel like, displaying the famous ' fighting attitude' in order to meet the expectations of self and the others, struggling not to feel anxious or depressed even if the person is collapsing on the inside can lead to loosing confidence in one's ability to influence the course of cancer and place a huge baggage of undeserved and unjustified guilt. In this context, Spiegel's affirmation, although very well intended, that 'in our desire to be respected members of the oncology community, we have often minimized a natural ally in the battle against cancer – the patient's physiological stress-coping mechanisms'(Spiegel, 2012, p 588) seems rather ironic. Thus, as Coyne et al. (2007) points out, if psychological interventions do not prolong survival, acknowledging it would remove some of the blame felt by persons with cancer.

These issues should lead to a serious debate as to future direction of psycho-oncology. If it strives to still search for potential benefits of psychosocial interventions on survival, more attention should be devoted to designing adequately controlled trials . Even if interventions and personality traits do prove to influence survival, the field faces the challenge of finding good answers for the questions regarding the ethical implications of such discoveries. Should patients with cancer prone personality traits be advised to enroll in therapy? Would cancer development be more under their personal control and if so, could they be held (at least partially) responsible for the outcomes? Until we find answers to such provocative questions, the field should devote itself to understanding the mechanisms by which these interventions influence psychological outcomes. Also they should focus on refining and tailoring existing interventions as to maximize their potential psychological and psychosocial benefits that may seem, at a superficial analysis, less intriguing or challenging. Tackling patients' emotional distress, boosting their social functioning and self-management skills (psychological

management of pain, fatigue, nausea etc.), facilitating a better quality of life and quality of death should be regarded as being equally important psychosocial outcomes as prolonging survival.

References

Bleiker, E. M. A., Hendriks, J. H. C. L., Otten, J. D. M., Verbeek, A. L. M., & Van der Ploeg, H. M. (2008). Personality factors and breast cancer risk: A 13-year follow-up. *Journal of the National Cancer Institute, 100*(3), 213-218. doi:10.1093/jnci/djm280

Butow, P. N., Coates, A. S., & Dunn, S. M. (1999). Psychosocial predictors of survival in metastatic melanoma. *Journal of Clinical Oncology, 17*(7), 2256-2263.

Butow, P. N., Coates, A. S., & Dunn, S. M. (2000). Psychosocial predictors of survival: Metastatic breast cancer. *Annals of Oncology, 11*(4), 469-474. doi:10.1054/bjoc.2000.1471

Coyne, J. C., Stefanek, M., & Palmer, S. C. (2007). Psychotherapy and survival in cancer: the conflict between hope and evidence. *Psychological Bulletin, 133*(3), 367-94. doi:10.1037/0033-2909.133.3.367

Coyne, J.C., & Tennen, H. (2010). Positive psychology in cancer care: bad science, exaggerated claims, and unproven medicine. *Annals of Behavioral Medicine, 39*(1), 16-26. doi:10.1007/s12160-009-9154-z.

Diamond, J. (1998). *Because cowards get cancer too: A hypochondriac confronts his nemesis*. New York: Random House.

Fawzy, F. I., Canada, A. L., & Fawzy, N. W. (2003). Malignant melanoma: Effects of a brief, structured psychiatric intervention on survival and recurrence at 10-year follow-up. *Archives of General Psychiatry, 60*(1), 100-103. doi:10.1001/archpsyc.60.1.100.

Fawzy, F. I., Fawzy, N. W., Hyun, C. S., Elashoff, R., Guthrie, D., Fahey, J. L., et al. (1993). Malignant melanoma: Effects of an early structured psychiatric intervention, coping, and affective state on recurrence and survival 6 years later. *Archives of General Psychiatry, 50*(9), 681-689. doi:10.1001/archpsyc.1993.01820210015002

Garssen, B. (2004). Psychological factors and cancer development: evidence after 30 years of research. *Clinical Psychology Review, 24*(3), 315-338. doi:10.1016/j.cpr.2004.01.002

Greer S., Morris T., & Pettingale K. (1979). Psychological response to breast cancer: effect on outcome. *Lancet, 314*(8146). 785-787. doi:10.1016/S0140-6736(79)92127-5

Greer, S., Morris, T., Pettingale, K., Haybittle, J. (1990). Psychological response to breast cancer and 15year outcome. *Lancet, 335*(8680), 4950. DOI: 10.1016/0140-6736(90)90173-3

Keller, B. (2014, January 12). Heroic mesures. The New York Times. Retreived from http://www.nytimes.com/2014/01/13/opinion/keller-heroic-measures.html?_r=0

Lepore, S. J. & Coyne, J. C. (2006). Psychological interventions for distress in cancer patients: A review of reviews. *Annals of Behavioral Medicine, 32*(2), 85-92. doi:10.1207/s15324796abm3202_2

Morris, T., Pettingale, K.,& Haybittle, J. (1991). Psychological response to cancer diagnosis and disease outcome in patients with breast cancer and lymphoma. *Psychooncology, 1*(2), 105114. doi: 10.1002/pon.2960010207

Nakaya, N., Bidstrup, P. E., Saito-Nakaia, K., Fredriksen, K., Koskenvuo, M., Pukkala, E.,..., Johansen, C. (2010). Personality traits and cancer risk and survival based on Finish and Swedish registry data. *American Journal of Epidemiology, 172*(4), 377-385. doi: 10.1093/aje/kwq046

Petticrew, M., Bell, R., & Hunter, D. (2002). Influence of psychological coping on survival and recurrence in people with cancer: systematic review. *British Medical Journal,*

325, 1-10. Retreived from http://www.bmj.com/content/325/7372/1066.1.pdf%2Bhtml

Pettingale K. (1984). Coping and cancer prognosis. *Journal of Psychosomatic Research, 28*(5), 363364. doi:10.1016/0022-3999(84)90066-7

Schulz, R., Bookwala, J., Knapp, J. E., Scheier, M. , & Williamson,G. M. (1996). Pessimism, age, and cancer mortality. *Psychology and Aging, 11*(2), 304-309. doi:10.1037/0882-7974.11.2.304

Spiegel, D. (2012). Mind matters in cancer survival. *Pyshcooncology, 21*(6), 588-593. doi: 10.1002/pon.3067

Spiegel, D., Bloom, J. R., Kramer, H. C., & Gottheil, E. (1989). Effect of treatment on the survival of patients with metastasic breast cancer. *Lancet, 334*(8668), 888-891. doi:10.1016/S0140-6736(89)91551-1

Temoshok, L. (1987). Personality, coping style, emotion and cancer: towards an integrative model. *Cancer Surveys, 6*(3), 545-567. Retreived from http://legacy.library.ucsf.edu/tid/drx03a99/pdf

Temoshok, L., Heller, B. W., Sagebiel, R. W., Blois, M. S., Sweet, D. M., DiClemente, R. J. & Gold, M. L. (1985). The relationship of psychosocial factors to prognostic indicators in cutaneous malignant melanoma. *Journal of Psychosomatic Research, 29*(2), 39-154. doi: 10.1016/0022-3999(85)90035-2

Tschuschke, V., Hertenstein, B., Arnold, R., Bunjes, D., Denzinger, R., & Kaechele, H. (2001). Associations between coping and survival time of adult leukemia patients receiving allogenic bone marrow transplantation. Results of a prospective study. *Journal of Psychosomatic Research, 50*(5), 277285. doi:10.1016/S0022-3999(01)00202-1

Watson, M., Haviland, J. S., Greer, S., Davidson, J., & Bliss, J. M. (1999). Influence of psychological response on survival in breast cancer: A population-based cohort study. *Lancet, 354*(9187), 1331-1336. doi:10.1016/S0140-6736(98)11392-2

Watson, M., Homewood, J., Haviland, J., Bliss, J.M. (2005). Influence of psychological response on breast cancer survival: 10-year follow-up of a population-based cohort. *European Journal of Cancer ,41*(12), 1710-1714. doi:10.1016/j.ejca.2005.01.012

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