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1998

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Ethical Issues in Communicating with Participants

ISSN 1430-1148

1. The Attitudinal Context of Communication with Participants

Communication is imbued with attitudes toward the addressees and conscious or unconscious conceptions about the relationships with them. Sensitivity for ethical conflicts as well as "handling" them largely depend on the views the "subjects" "used" in research as well as on the relationships with them. Riegel (1979) as well as Baumrind (1980) have criticized the use of the term "subjects", and they proposed, among others, to replace it by the term "participant" since this concept implies the view of a person who has freely chosen an active role in the process of research. The question is whether we are aware of the kind of contribution participants make. I would like to suggest a perspective that I feel is appropriate in approaching ethical problems in research.

Although there are examples of research from which some of the participants benefit, it would be more truthful to focus on the gains expected by the researchers for their careers and their prestige, or by the agencies or institutions interested in the results of research, and by the community and mankind interested in useful knowledge. In all cases, researchers, agencies, and the community are dependent on participants - there are only some cases in which dependency is reciprocal - and sometimes they take advantage of the participants without compensating them adequately. Research would be much more expensive if the usual standards of fair and equitable compensation for the time spent, for efforts, experienced discomforts, objective risks, and so forth would be observed.

Consequently, participation frequently is a prosocial activity, an act of help. I doubt whether the majority of researchers is aware of the fact that they depend on the help of participants, and that the participants are not at all obligated to grant their support. Preparing this paper, I was looking for cues of researchers' indebtedness to participants in publications, including my own. I found acknowledgments to funding agencies, to colleagues and assistants, but none to participants. I remember that I have come across a few exceptions but I am not able to cite them just now. I feel quite certain that most researchers express their thank to the participants as a routine, but if this was done explicitly in publications it would certainly increase the awareness of the fact that participants do play an important role in research in general, and that they have to do this "prosocially" meaning without adequate compensation. Research is benefiting from participants whereas the reverse is true only exceptionally. I could imagine that keeping this "fact" in mind would create an attitude toward participants that would help to respect their rights in dealing with ethical dilemmas that are unavoidable in research.

However, this view certainly does not mean to claim "all rights to the participants". Though it is true that researchers and the community are indebted to participants, it does not imply that participants are free to withdraw from a project at any point they feel like. In fact, participation is a freely chosen commitment, but researchers may trustfully expect their "subjects" to stay to the end of the project. Commitment creates obligations. The researcher invested time and other resources to collect and process the data, and this obligates the participant to continuous, reliable and responsible cooperation unless withdrawal would be justified by acceptable grounds. Though participation should be freely decided, once it was decided it can well be conceived analogously to a contract with reciprocal responsibilities especially in prospective longitudinal studies.

The reason why I put these reflections at the beginning of my talk is that I am convinced that ethical dilemmas cannot be resolved by rigidly applying concrete ethical rules as they are found in the guidelines mentioned in the next section. For instance, giving comprehensive information about all aspects of the research to those who were asked for participation is impractical, and it is ethically doubtful in many cases. I shall discuss this later.

The preoccupation with the ethical requirements focused on specific issues during the last decades such as obtaining informed consent, assuring freedom from coercion to participants, avoiding to cause them physical and mental strain, securing anonymity and confidentiality, and so forth. I think that many of these requirements do not necessarily have to be regulated by a set of specific rules. They would, instead, grow as a matter of course out of a view that does not perceive participants as "subjects" but as responsibly cooperating participants. This view cannot be imposed normatively by some "thou shalt" or "thou shalt not". No such rules could replace a "culture of research" in which the participants are considered to be cooperating partners within a relationship of mutual responsibility.

As the recommendations of the American Psychological Association (APA) from 1973 concede, ethical norms are not absolutely valid or obligatory with respect to concrete cases. Ethical conflicts (dilemmas) as well as conflicts with ethical norms are unavoidable, and they are to be solved within a research culture of respect for the dignity and the welfare of the participants.

The recommended ethical rules are suggestions to be weighed in any time an ethical conflict has come up that, ideally, has to be solved in discourses in which the rights and options of participants as well as those of the researcher and the community are considered. In such discourses ethical rules apply that are not concrete prescriptions of how to behave or not to behave. Instead, these are rules about how to proceed fairly, how to meet the other parties, how to consider and to communicate about their options, and how to communicate about own options. Guidelines for ethical discourses are found in the philosophy of ethics (Rawls, 1971 Habermas, 1983 Lorenzen & Schwemmer, 1975) as well as in treatises of procedural justice (Thibault & Walker, 1975 Tyler, 1990).

Of course, the researcher cannot engage in discourses with all participants, and boards are not everywhere to discuss ethical problems in every single project. The researchers have to reflect the conflicting rights and options themselves, and they should observe the same principles of fairness in their own thinking that are to be observed in formal discourses when they design a study and communicate with participants.

I would like to suggest to consider participants as responsible and voluntary contributors to the process of research, who are frequently not rewarded with adequate external benefits. I am sure, this would help to prevent abuse.

2. Ethical Recommendations

Concrete ethical rules for research are derived from basic human rights such as the right to welfare, to freedom, and to privacy. The ethically recommended communication with prospective participants will have different goals depending on the stage of research.

(1) At the stage of recruiting participants, all persons addressed will have to be informed about purposes, procedures, confidentiality, costs, risks, etc. before their consent to participation will be asked for.

(2) Prior to the start of the consecutive waves of a longitudinal investigation the participants have to be informed about all changes in the project that might be reasonably relevant for the decision to continue participation. When children are participants it will depend on their growing age whether their consent or "assent" has to be asked for. Moreover, problems that are arising because of the participation as well as possible desires to withdraw from the investigation have to be handled at that time.

(3) After the collection of data has been finished all participants need to be informed about possible deceptions or concealments ("debriefing"). They have to be offered the possibility to withdraw their data if they were not able to accept the reasons for deception. Problems that have come up through participation - disturbances of health or psychic or social problems, often indicated by negative emotions such as anxiety, resentment, shame, guilt, irritation, feelings of inferiority, have to be discussed or dealt with. Participants have to be assured again that their data will be treated confidentially, or whether or not an anonymization of their data had been realized.

Concerning contents and forms of the communication with participants, most of the requirements for obtaining informed consent are formulated in the 1971 Guidelines of the Department of Health, Education, and Welfare in the USA:

(1) A fair and understandable explanation of the nature of the activity, its purpose, and the procedures to be followed, including an identification of those that are experimental.

(2) An understandable description of the attendant's discomforts and risks that may reasonably be expected to occur.

(3) An understandable description of any benefits that may reasonably be expected to ensue.

(4) An understandable disclosure of any appropriate alternative procedures that may be advantageous for the participant.

(5) An offer to answer any inquiries concerning the procedures to be used.

(6) An understanding that the person is free to withdraw his or her consent and discontinue participation in the project or activity at any time without prejudice.

Several additional requirements were proposed (Levine, 1975 Reiss, 1976):

(7) An invitation (as opposed to a request or demand) to become a participant along with a clear definition of the role the person is being asked to play as a participant.

(8) Informing the prospective participant as to why he or she has been selected, including any consequences of being found eligible.

(9) An offer to the potential participant of consultation with a third party during the decision-making process.

(10) Obtaining consent to any incomplete disclosure of the purposes of the investigation and of the procedures that will be used.

(11) Informing the participant about to whom information will be given.

(12) Informing the participant about the sources of financial support.

- (13) Informing the participant about possible limits of data confidentiality.
- (14) Informing the participant about the reasons for disclosure of deception when practiced.

The Department of Health and Human Services (1981) added some more: The participants should be

- (15) informed about the availability of compensation and treatment if injury occurs,
- (16) given instructions as to who may be contacted for answers to pertinent questions,
- (17) informed about possible additional costs to the participants,
- (18) about the consequences of participant's withdrawal,
- (19) about the approximate number of participants in the study,
- (20) about significant new findings gained by the designed research.

Observing these ethical standards rigidly would limit the realm of what could be investigated enormously. There are well-founded claims for exceptions from a generalized strict application of these rules. Indeed, their application would raise ethical dilemmas in research that would have to be treated discursively and that cannot be decided upon by strictly applying rules that are set absolutely.

2.1 Informed Consent as an Ethical Demand

(a) What should participants be informed about?

During the Nürnberg process, a code was formulated that should be considered as a system of rules that were to be applied in the pursuit of medical research. Based on this code, 23 physicians were sentenced because of crimes against humanity. The sections that are relevant to the principle of informed consent read as follows:

"The voluntary consent of the human subject is absolutely essential. This means that the person involved should have legal capacity to give consent should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision. The latter element requires that before the acceptance of an affirmative decision by the experimental subject there should be made known to him the nature, duration, and purpose of the experiment the method and means by which it is to be conducted all inconveniences and hazards reasonably to be expected and the effects upon his health or person which may possibly come from his participation in the experiment. The duty and responsibility for ascertaining the quality of the consent rests upon each individual who initiates, directs, or engages in the experiment. It is a personal duty and responsibility which may not be delegated to another with impunity."¹⁾

This code is set absolutely as far as the consent for participation is concerned, and it does not allow for any exceptions. Its basis is two interrelated ethical principles: (1) The individuals' right for self-determination which implies that any invasion into a person's body or privacy requires his or her voluntary consent, and (2) the obligation of the researcher to inform the participant about all aspects of the investigation that reasonably seem to be relevant to his or her decision, so that the participant's subsequent consent is given knowingly. This would prevent the infliction of injustice to the participants according to the principle in Roman law: *Volenti non fit injuria*. However, it does not necessarily prevent the infliction of harm! The participant has the right to voluntarily and responsibly accept the risk of harm.

Later formulated recommendations such as the Declaration of Helsinki adopted by the World Medical Association (1964), or that of the Department of Health, Education, and Welfare (1971), the National Commission for the Protection of Human Subjects of Biomedical and Behavior Research in the USA (mid seventies), the Codes of the American Psychological Association (1973, revised 1981) and of the American Sociological Association (1982) are all influenced by this Nürnberg Code (Keith-Spiegel, 1983). Nearly all of the 20 requirements mentioned before are regulating the contents of information to be communicated before asking for the consent to participate.

(b) Informed consent and responsibility

The demand to inform the (potential) participant is - as I feel - derived best from Kant's categorical imperative "to never use a human being as a means to an end". Human beings are free to choose their own ends, and it would mean to neglect their freedom - we usually speak of the

human right to freedom - to use them for an end they had not chosen. Choice presupposes information about the alternatives. Without information the "choices" are not reasoned.

Human beings are responsible for their choices and the foreseeable subsequent consequences. Responsibility results from the freedom to choose between alternatives, for instance, to participate or not to participate in research. The choice to participate in a research project presupposes information about the project as well as about participation. These information are available to the researcher. Unless they are conveyed to the participant, neither the participant nor the researcher will know to what consent was given. A highly important question is: Is an uninformed consent a responsible decision? Perhaps the participant had an erroneous idea of what the research he/she consented to participate in would be. Is he/she responsible for participating? This might depend on the answer to the question: Who is responsible for the erroneous idea about the research?

It seems like we have to consider two issues: (1) the human right of the participant to free (implying responsible) decisions, meaning he/she will not be (ab-)used as a means to the researcher's ends, and (2) the responsibility for participation and its subsequent consequences if comprehensive information about the research had not been given.

I would like to propose the following thesis: The researcher is morally responsible for every harmful consequence caused or induced by participation except when it was unforeseeable or when the possible risk was known to the participant and he/she had accepted it voluntarily. Thus, providing information to the respondents before obtaining their consent not only serves to protect their rights, it also discharges the researcher from the responsibility for the participant in case of harm.

Of course, it is not just the participant who has the human right and the ability to make free decisions, the researcher, too, has this right, for instance, to inform the participants incompletely, or to deceive them. In this case, however, the researcher keeps the responsibility for the participation and its subsequent consequences. This responsibility may only be transferred to the participants when the researcher informs them, and they consent voluntarily. The researcher may have good reasons - scientific ones as well as altruistic ones - to conceal information. When he/she decides to do this, it is a decision he/she is responsible for.

Following this view, some questions are emerging to the issue of informing about the research: (1) Is it possible to inform comprehensively? It is not for more than one practical and ethical reason. What does this demand mean? Is it the information to be offered or is it received information? Understanding depends on knowledge, on the language used, on interests and consciousness, and so forth, reception depends additionally on factors like trust, anxiety to be harmed, and so forth. There are a couple of studies on understanding and remembering information presented by researchers that show that there are certainly a lot of interindividual differences, but they also show that most respondents did neither read detailed informational material carefully, nor did they fully understand it, and the recall was poor, too (Epstein & Lasagne, 1969 Faden & Beauchamp, 1980 Stanley et al., 1987). The researcher might be legally safe-guarded when he/she had informed truthfully and had obtained the consent of participation in a written form. Morally, this might not be enough. The researcher should try to find out how much of the

information was actually received and understood, whenever risks and costs are reasonably expected. To be sure that the participant takes the responsibility to participate, information about risks and costs have to be transmitted effectively.

(2) One might argue that offering the participants to answer their questions will be ethically sufficient. The arguments are: Any information not asked for does not have to be given. The participant is free to ask every question, and he/she is responsible for asking or not. Participants will not be overloaded with information that they are not interested in. To this last point, there is empirical evidence that many participants are not interested in comprehensive information.

The ethical limitations of the procedure are obvious. In relation to the participants researchers have responsibilities. Since they are asking for participation, since they will benefit from participation, and since they have better knowledge of possible burdens and risk the responsibility is left with them until participants will be effectively informed. The researcher will also have to keep in mind that participants do not act irresponsible when they consent in good faith not to be harmed or abused unless they were warned before. This, again, burdens the researcher with the responsibility for informing the participants, or else, for any harm being done to them.

(3) There are several reasons for not informing participants about every aspect of the research such as to avoid unnecessary worries for the participants or to avoid impairing the validity of the research. This will be discussed in more detail later. It has been suggested to inform the participants about the fact that they will not be fully informed for good reasons. Is the consent to participate equivalent to "informed consent" in this case? I think, it depends. It is not when the worst consequences a participant may reasonably imagine are significantly less severe than the real consequences will be. Therefore, there should be some exchange of information about the possible harm or discomfort.

In principle, however, I would concede freedom of consent to participants if they knew that they were not informed about the research in detail. To secure the participants' right to welfare, however, researchers should consider whether the procedure has to be approved by an independent board of "trustees".

(c) How should participants be informed?

As far as the communication with participants is concerned, there is one important issue widely missing in the ethic guidelines: they lay down what the contents are that the participants will have to be informed about but as far as the form of the information is concerned there is not much more than the term "understandable" to be found. For the legal security of the researcher (to be protected against summons by participants), it might be enough to inform about anything reasonably relevant for the decision whether or not to participate. If the true meaning of the ethical demand for informed consent is taken seriously, however, then the How? of communicating the information as well as the psychology of decision making have to be considered, too. The context, the sequence of information, strategies of persuasion and motivation, the personality, state of health of the participant, the relationship to the researcher, all that is important - but for all these questions there are no regulations.

The model of a rationally deciding person searching for all relevant information and digesting them seems to have been the basis for the recommendations. I think, this model does not re-

present the majority of research participants as is evidenced by the empirical studies cited above. Neither the consent nor the refusal to participate did seem to be due primarily to the content of received and recalled information about the purpose, procedures, and risks of the inquiry (summarized in Stanley et al., 1987). It does in fact seem to be rather unusual that the decision making process is a process of rationally weighing and integrating all available information. More often, it seems like a rather spontaneous act, determined by "feelings", that later might be justified by some of the information recalled.

Yet, even if we assume that this would happen frequently, it would not cancel the basic right of the participants to disclosure of all relevant information. But in any case, the researcher has a good chance to obtain consent from participants in spite of "informing" about costs and risks because these information were not received and considered adequately. That means, even if the researcher would have provided all the information prescribed in the ethic guidelines it would not imply that he/she had gotten the participants consent in an ethically unobjectionable way.

Various aspects of communications with participants

There are several aspects to be distinguished in communications: (1) the factual content, (2) the kind of social relationships between the communicating individuals, (3) the expression of feelings, status, self-images, etc., and (4) requests and appeals to the recipient (Schulz v. Thun, 1986). When communicating with participants these aspects have to be distinguished.

(1) The factual content is coded verbally, e.g., information about the purposes of the research project, the procedures, the tasks of the participants, possible strains and benefits, the scientific value of the project, and so forth.

(2) The aspect of relationship may be communicated both verbally and nonverbally. It may be evidenced by various dimensions such as perceived status of both the researcher and the participant, researchers' concern for or attitudes toward the participants, and so forth.

(3) The expression of feelings and emotional states of researchers is transmitted, too, when they communicate with participants, when, for instance, they express enthusiasm about their project and commitment to an important scientific purpose, when they present themselves as competent and responsible authorities, when they disclose how much they would appreciate a consent to participate, or when they express disappointment or even anger at a respondent who refuses participation or who withdraws from an ongoing study.

(4) Some of the expressed cues may yet imply appeals and requests to the recipients beside the factual content of the requests communicated verbally expectations including normative ones, entitlements of the researcher in case participants wish to withdraw, all these things may be communicated.

The communication with participants can be analyzed by distinguishing these aspects. The content of verbally coded information is only one of these aspects. The regulations found in the ethic guidelines are only concerning the content of the communication. The other aspects including self-presentation in the sense of being a scientific authority, appealing to prosocial motives, to be ingratiating, to suggest trustworthiness, all these may be means and tactics of persuasion that have an impact on participants' decision making.

I would like to point to only one aspect - the relationship between researcher and participant that may moderate the weighing of every factual information. If the participants would perceive the researcher as a responsible, considerate authority, they would trust him/her and would not critically read, reflect, and weigh the disclosed information about the project. If they perceived the relation to the researcher as close, they would hesitate to refuse participation or to withdraw from the study even if participation turned out to be burdening and discomforting. If the relationship were considered rather businesslike there would be no personal motives to comply. If the relationship was perceived exploitative, there would be more reactance to comply than if it was perceived cooperative, and so forth.

Researchers have many possibilities and tactics, not only verbal ones to weigh, to emphasize, or to conceal information and to motivate potential participants. Can a researcher be blamed for trying to persuade people to consent? What means and tactics are forbidden, which are not? Is it allowed to use incentives (financial compensation) or manipulative techniques like the ones social psychology has described (ingratiation, claiming authority, foot in the door-technique, appeals to altruism, and so forth). Are the prestige of science, the objective authority of a researcher, his/her enthusiasm and involvement undue influences? Is it wrong to profit by the trust of respondents in authorities? Is it a subtle form of coercion to offer potential participants no other preformulated alternative answer than the "yes" to participate? (Rosen, 1977, demonstrated that respondents consent far more frequently when they are not given other options to answer. For many people it seems difficult to refuse a request when the category "no" is not offered as an equally acceptable alternative to "yes", whereas compliance would be immediately rewarding.). It certainly is difficult to differentiate between acceptable persuasion and undue inducements.

The ethical guidelines are not very explicit about the "how" of communication. There are appeals for fairness, but what might be considered unfair? Since I do not have a ready made answer to this question I would like to point again to the question of "Who is responsible for participation and for subsequent consequences, the researcher or the participant or both?".

The researcher is obligated to inform the participant because of the participant's right to be informed. However, the adult, mentally healthy participant is not obligated to consider and to use the information provided. Parents and guardians who are asked vicariously to give consent to participate for their children and wards do have the moral responsibility and the obligation to consider the given information very carefully.

Legally, it is sufficient to provide understandable information about all aspects of research that are relevant for decision making, and to get (written) consent to participate. Morally, it is not sufficient to provide these information. It should be ensured that the information are understood and considered before researchers may transfer the responsibility to the participants or their proxies. Consequently, any persuasive communication, any profiting from prestige, authority, or readiness to trust, any biased communication that focuses, for instance, on possible benefits by participating, and any concealment of risks will burden the researcher morally with the responsibility (a) for expected harm that is occurring as well as (b) for a later withdrawal from participation because of unexpected discomfort or harm.

With his or her consent to participate after having been informed about possible costs and risks, the participant takes responsibility for their occurrence however, some qualifications to this are in order:

(1) It has to be ensured that the consent will be given freely, i.e., that it will not be given in a state of urging need (e.g., a financial need in case there is a monetary reward offered for participating), or because of a felt obligation (e.g., of a patient to his physician/researcher at a University Clinic), or in a state of emotional and cognitive disturbance.

(2) Not all costs and risks will be included, only those that are explicitly mentioned.

(3) Mentioning of possible risks does not imply that the researcher is free of the responsibility to cure or compensate the participant in case that harm really occurs this point has to be negotiated and clarified in advance.

(d) Freedom of decision and self-responsibility

The ethical guidelines are explicit inasmuch as consent has to be given voluntarily, without coercion and intimidation. No other threat to a really free decision is forbidden explicitly. There are, however, some other cases that bear ethical problems.

The promise of benefits: The APA code (1973) stipulates that "priority must be given to the research participant's welfare ... that the risks are minimal ..." and "if possible, participants should enjoy an identifiable benefit." (p. 11).

Of course, there might be several positive consequences of participation which could be mentioned, such as (1) the satisfaction to have contributed to gains in knowledge (2) gaining important information about oneself (3) acquiring new competencies (like, for instance, in a speech or memory training) (4) a gain in health (for example by participating in the clinical testing of a new drug to reduce cholesterol, or in a study about the effects of a certain diet) (5) when participation is intrinsically animating or when it offers pleasant side effects (like being reimbursed for trips to a beautiful university city) (6) financial compensation and so forth.

May benefits be promised? Reflecting on ethical problems, I feel rather uneasy with the promise of benefits. When benefits can be reasonably expected (e.g., training effects) or offered (e.g., a pay), then this, per se, is not problematic ethically.2) Ethical problems arise when the benefit is a promise to overcome fears of risks or when the promised benefits are disguising risks that may be reasonably expected. These problems will not be solved by obtaining the formal "informed" consent of the participant.

Juridically, if we assume that the participant was really informed and that he/she had reasonably weighed the costs and risks in his decision against the benefits for him- or herself (perhaps for his or her child or for mankind in general) then there would be no injustice: A free and responsible decision eliminates injustice. Juridically as well as philosophically, the assumption of freedom of decision should not be dismissed just because there are more or less strong motives to come to a specific decision. It is an apriori assumption that everybody should be considered to have the freedom to consent or to refuse, even if, for instance, poor people might be more seducible by being promised a small pay, or if people in crises or with personality problems are more seducible by being promised therapeutic benefits, or if a severely ill patient might be more

seducible when he is given the hope to be cured. Even if it was known that most healthy young people have a sense of invulnerability, and that they do not care much about minor risks to their health, it might be assumed that their consent to participate had been freely (implying responsibly) decided.

However, the assumption of freedom and responsibility may be questionable.

Suppose, a medical researcher plans a study that involves a considerable risk for the participants. The society would allow to recruit prisoners to participate, and would grant them a reduction of time in jail as a benefit for participation. From the point of view of the prisoner, consent to participate may be freely chosen and responsibly decided on. But can the offer be justified ethically? Do we not use a human being for society's purposes, merely pretending to grant freedom of choice?

This illustrates that we need discourses about the question who is psychologically free to make a responsible decision. Under the heading "Communication with participants", it is ethically not too rigorous to at least require that the information about reasonably expected risks and costs is not only given explicitly but that care should be taken that these information are fully understood by the respondents. This requires to use an understandable language and to avoid disguising these information. There are several forms to disguise information, for instance, by placing them at the end of a lengthy text, by using a scientific terminology, by adding calming comments with respect to probability and security, and by emphasizing the benefits.

Moreover, the promised benefits have to be clearly identified in advance. Of course, participation in research will be an experience, and it is true that every experience, including the experience of harm and loss, may challenge and stipulate development: Some people will be able to derive benefits even from stressing experiences. But may we promise this?

Objections against the promise of benefits and useful feedback

Benefits may be derived from assessing developmental or health indicators (useful to prevent disturbances or to discover them early), or they may be positive effects of interventions or counseling.

To begin with the latter, there are examples of evaluation research in which the best knowledge available was used to design a training, a diet, or a therapy to be evaluated. The procedures correspond to the best practices known. For instance, many of the early cognitive training programs used the best available knowledge (Schmidt-Denter, 1987). Every informed practitioner would have designed similar educational programs. Research is evaluation of the best known practice. In these cases, benefits may be reasonably expected for participants who do not belong to the control group.

Benefits might be derived from the information about the results of assessments, too. Especially in medical research it seems to be easy to give participants a hint to consult their physician whenever a symptom of pathology is observed.

There are developmental and epidemiological projects that have resources at their disposal that allow for adequate care and counseling whenever a symptom is observed with a participant (Rolf & Hasazi, 1977).

Generally however, researchers should be very careful and cautious in promising benefits. The promise of benefits does not seem to be indicated when the research is done to test the validity of measures or to test the effects of interventions that are hoped to be only positive even though the empirical results have to be awaited to be sure that there might not be negative side effects and the positive effects will really occur. In communicating with participants it should clearly be pointed out that it can not be expected to have confirmed results available very soon. It has to be made clear that as of now nobody knows what is right and what is wrong, that the participants help to find that out without being able to use this information for themselves directly.

Instead of promising personal benefits, it would be responsible to mediate the basic scientific attitude to participants: Research is looking for empirical information knowledge is searched for empirically, it cannot be deduced validly from existing theories. Participants help to gain valid knowledge. It is not available before research is done, and therefore, personal benefits cannot be promised.

3. Problems with individual feedback

One of the supposed benefits for participants is the chance to obtain valuable feedback about assessments. I shall not contest that feedback may be beneficial in individual cases such as feedback about pathological findings or about early indicators of deviance or of emotional disturbances. However, several reservations should appropriately be made:

- The primary goal of research is to advance knowledge. Giving feedback to the participants between the waves of a longitudinal research might interfere with the scientific goals and impair the validity of the study. Except for instances in which feedback would prevent an impending threat to the participants one should be very cautious with giving feedback. In many research projects feedback might influence the motivation to continue participation and cause selective drop out, or it might motivate to change one's own life or to seek counsel or cure, to start a therapy, a training, or an education, and so forth. All this may contribute to the error variance of the key measurement variables of the study.

- Feedback to the participants about the results of the assessment could be problematic because it might induce problems or it might not be adequately comprehended. Without offers of interpretation and counseling, any feedback of results is irresponsible.

- Valid feedback can only be promised when assessment procedures are used for which the validity had been tested empirically. If however, validity has to be established first by the ongoing research, feedback is to be postponed until this is done.

Therefore, it should be ensured that the promise of feedback would not have the effect that participants might forfeit their usual medical checkups and sensible observations of possible symptoms of disturbances.

4. Awareness of Duties, Risks, and Costs

Up to now, strains and stresses, risks and burdens have often been mentioned. What are they? Do they occur frequently? Are they not overemphasized in debates about the ethic of research?

The participation in an investigation may, of course, have straining and stressing impacts such as demands on one's time schedule through the obligation of contract-like work in the regular accomplishment of tasks that were agreed upon (e.g., sticking to a regular diet, exercising regularly, keeping a regular diary on every personal experience and on everything that happened). Especially in longitudinal studies it is expected that all participants stay with the investigation throughout all planned waves of assessment or treatments, that they inform the researcher when they move to another city, and so forth.

In addition to these foreseeable duties and burdens there may be various risks and costs. Using the distinction between descriptive and manipulative studies, I will mention some of them, mainly to draw attention to the possible risks in psychological and social science research in which these aspects are notoriously underestimated.

In descriptive studies, participants have to respond to items in questionnaires and interviews, they have to accomplish tests of various kinds, they undergo several diagnostic procedures in medical and epidemiological research. Except for some invasive and radiological diagnostic procedures in medical research, there are no direct risks to one's health to be expected in descriptive studies. But some stressful consequences are to be considered:

- recollection of unpleasant experiences such as the death of a beloved, imprisonment, injury, humiliation, defeat, and the revival of associated emotions such as sorrow, pain, anxiety, injustice, and so forth
- being afraid that expressed opinions about topics, people, parties etc. might cause disadvantages, discrimination, and stigmatization if they became public in some countries they could even start political persecution
- being afraid that confidential information about undiscovered deviant behavior (e.g., offenses, drug abuse) or about former illnesses and defects may become known and lead to disadvantages
- problematic interpretations of own experiences and behavior induced by answering questions and readings items: responding to a checklist of pathological symptoms or tormenting questions for negative experiences, emotions, and burdens may, for instance, suggest a feeling of vulnerability, of a threatening danger, or of a hidden illness that may have detrimental effects on mental health
- problematic egocentric interpretations of being selected to be a participant, including paranoid interpretations
- anxieties about the possibility that hidden attributes and convictions may be uncovered
- uncertainty about the fact whether in responding to unrevealing questions one has presented oneself in a socially desirable or favorable way
- feelings of shame and guilt when questions were answered extenuatorily false or marking answers just by chance since the contents had not been fully understood
- participants might become aware of conflicts, own weaknesses, emotions, vulnerabilities, dissatisfactions, feelings of injustice, and so forth that might not be easy to cope with

- when informed about results of the investigation and their interpretations, the question might arise: "Am I one of the good guys or do I belong to the bad ones?", for instance, with respect to educational practices, value orientations, abilities, achievements, coping competencies, personality traits, and so forth.

I suppose these examples demonstrate that participation in psychological and social science research, too, may cause a lot more stress and risks and may imply more than is commonly believed. It is not necessary to point to Milgram's experiments (Milgram, 1964) to demonstrate that problems with the self-image that last for months and years may be induced through the participation in a social psychological experiment (Schurz, 1989).

Of course, descriptive medical and epidemiological research that implies the assessment of individual styles of life, habits of nourishment, symptoms of illnesses, and diagnostical procedures may have problematic side effects, too: Participants may focus on phenomena as symptoms of illnesses, they will become aware of a certain vulnerability, they will build up false hypotheses about risks in their way of life, in their habits, and so forth.

In intervention studies risks are more obvious. Risks of intervention research are obvious in the medical field: Unknown side effects of drugs, of hormones, one-sided diets in the testing stage, and so forth. In addition to these, however, there are risks that are more subtle. Confidence in medical surveillance during the time of participation in a longitudinal study may cause a participant to neglect the usual preventive check-ups, or a delay in attributing symptoms correctly to illnesses instead of attributing them to the treatment administered in the study, and so forth.

There are also risks and burdens in social science intervention studies that should not be neglected:

- It is well known that through participating in psychological therapy studies problems might arise, or else, existing problems might become virulent without the chance to be treated adequately.
- When participating in training or schooling, feelings of failure might arise.
- The participation in an intervention study may interfere with the choice of more favorable treatments. This might be especially true for participants who are allocated to the control group that receives none or only minimal treatment.

I am not aware of extensive research on straining or stressing consequences of the participation. Therefore, researchers are in the state of benign ignorance. What is lacking today is research on stress that is experienced by research participants. Usually, communication with participants ends with the last wave of data collection or with the drop out of participants. A systematic exploration of experienced hardships is a rare exception. Studies on the motivation to drop out from longitudinal studies could be informative about this point.

If the rules for informing research participants about possible risks and burdens would be as strict as they are, in principle at least, for selling pharmaceutical preparates or for surgery, than all these risks - seldom as they may be - would have to be mentioned. Why has such a demand never been made in ethical guidelines for research?

In medical practice the potential risks have to be weighed against the hope of a gain in health. To balance the risk and the benefit is left to the patient and the consulting physician. Noticeable individual gains through participating in a research project are seldom. This allows the question whether the ethic commissions were afraid that researchers would be faced with enormous difficulties in recruiting participants for their projects if it was made an obligation to mention even rare risks. I would like to point to the implication again that reasonably expected risks - and seldomly occurring risks are not unreasonable ones - burden the researcher with the responsibility for compensation when they occur if they had not been mentioned prior to the request for consent to participate.

The promise of confidentiality in applied research

Let us look at an example. Among the stresses of participants are fears that confidentiality and anonymity of personal data might be violated. The risk of violation of confidentiality cannot be denied, it is objectively given.

"Should you ever be adventurous enough to do research on drug users, criminals, or youth gangs, or unlucky enough to have gathered data in an organization involved in a civil suit, you might join the growing list of social scientists whose data have been subpoenaed by one party or another. In most of the cases known, the researchers have successfully resisted the pressure without being cited for contempt or jailed (Bond, 1978 Culliton, 1976 Kershaw, 1975). But unless you are fortunate enough to fit into one of the narrow categories that offers a "testimonial privilege", your data have not special protection. The only guarantee of any promise of confidentiality you make may be your willingness to go to jail (Statistical Reporter, 1977 Breger, 1976)." (Murray, 1982, p. 85).

Promises of confidentiality seldomly have a rider "except as required by law". Researchers have the obligation to "inform participants who supply potentially sensitive information of whatever threats to confidentiality exist, and how far they - the researchers - are willing to go to protect them" (Murray, 1982, p.86). The sensitivity of educated people to the misuse of personal data has grown immensely in many European countries during the last decade. Nowadays, it is not easy to recruit educated people for participation in a research project on sensitive issues without clarifying first how confidentiality will be protected including the separation of names and addresses from data sources and the destroying of all identifiers as soon as the study will be finished.

The list of "hot issues" can be larger depending on the laws of the country: It may include personal data from medical, epidemiological, psychological, and sociological studies on epidemics like AIDS, or in sociological research on political orientations and activities.

If at all possible, an effective anonymity should be striven for. For longitudinal studies, however, all individual data collected in every successive wave of assessments need to be allocated to the previously collected data of the same participants. To grant anonymity makes it necessary to use codes, and this requires to build up and to safe-guard an allocation file of codes to names/-addresses. Of course, anonymity is endangered also when patterns of answers to questions, especially to demographic attributes, make an identification of participants possible. Therefore, superfluous demographic questions should not be included.

Researchers usually promise to grant confidentiality in treating the data. To believe the promise presupposes confidence in the researcher. To involve committees to inspect and supervise projects according to ethical points of view may establish additional confidence in the promise of confidentiality.

5. Deception and Concealment

There is no dissents about the ethical demand that deception of participants should be avoided. There is considerable dissents, however, whether (Baumrind, 1985) and when (Reese & Fremouw, 1984) exceptions can be allowed. In fact, as empirical analyses of the research practice in Social Psychology evidence, the ethic guidelines of the APA had not changed the research practice much. More than half the studies reported in the high ranked journals during 1979 and 1983 used deception (Adair et al., 1985), some of them implying stress and psychological risks. I do not have to evaluate, whether all these deception studies had investigated important questions. (In most cases they were done with students who did not care much about the deception.)

There are, however, important research questions that could not be investigated without deception. Milgram could not have studied the widespread tendency to comply with requests of authorities if the participants had been aware of the true purpose of the experiment.

Deception is usually considered permissible when

- the research question is an important one,
- there is no alternative for investigating it,
- the risks had been carefully weighed and evaluated by other researchers,
- adequate debriefing is provided in the course of which the participants are allowed to withdraw their data and to express any displeasure they might have with the deception.

Neither debriefing nor the right to withdraw the data nor to resent the researcher abolish the experienced harm in every case. Asking the participants' consent again to use their data after the debriefing session will give them control over their data but not necessarily control over the distressing experiences and of the consequences of having been deceived: They may resent the deception they may be disappointed to learn that they had gotten false positive feedback about their achievements or their personality they may distrust the debriefing in regards to whether it corresponds to the truth or whether it is merely another case of deception they may become aware of the fact that they had been abused as "subjects" or guinea pigs just to test a hypothesis instead of having participated as persons in an investigation. The debriefing of "subjects" in Milgram-type experiments did not alleviate the shame and the guilt about having complied with the immoral demands of the researcher (Schurz, 1989).

Longitudinal studies do not use the types of deceptions that are popular in Social Psychology including faking the real task, using confederates and pretending that they are "real" naive participants, giving false feedback and information etc. Not seldomly, however, will information be held back in longitudinal studies that could have been relevant for the consent. These cases of concealment would definitely counterdict some of the ethical requirements listed above if these

were set absolutely valid. Quite frequently, the true purpose and the issue of the study will not be disclosed to the participants, or only in very abstract and vague terms. I will discuss some cases, and I shall point to some justifications for this kind of deception.

Concealment of the true purpose of the study

To start out with, I would like to discuss the concealment of value laden research purposes and hypotheses. Many persons will only consent to participate when the purpose of a research project does not interfere with their basic value orientation. Questions like "Are there racial differences in intelligence?" "Are there prejudices against women in career professions?" "Are there psychic and somatic side effects of contraceptive pills?", and so forth might be rejected (1) because potential participants possibly reject an implication of the question (e.g., the assumption that the own attitude toward career women might be prejudicial), or because (2) they might be afraid of empirical results that contradict their own world view and value orientations (e.g., existing racial differences in intelligence), or (3) because they suspect a value orientation of the researcher that they refuse (e.g., the researcher is suspected to be a racist or a feminist or a papist who is searching for evidence to damn the pill). Participation might be refused for all three reasons.

The second case I would like to discuss is the concealment of anxiety provoking research purposes. Think of prospective longitudinal research with representative samples on the causation and incidence of heart diseases, cancers, on the incidence and coping with critical life events like death of a beloved, accidents, economical losses, victimization by criminal offenses, on the decline in old age: There may be many people who refuse to participate because they do not want to think about these possible injuries and hardships. Participation would imply being repeatedly reminded on own vulnerability.

Not informing participants about the questions, purposes and hypotheses of a project is a common practice. Concealing the true intentions is especially common when participants will be recruited from a social category for which comparatively negative information (e.g., low achievements, vulnerability) are expected in the research project. The questions investigated will become publicly known through later publications, therefore one cannot be sure that they can be concealed permanently. Moreover, debriefing is not unproblematic ethically and one cannot be sure that the participants will accept the reasons why they have not been informed: When they do not, they will mistrust researchers later on. One recommendation (APA, 1973) was to communicate with participants in a way that they will not refuse cooperation in another research project.

To conceal the true purpose of the research would be ethically doubtful if the only reason for it would be to obtain many consents for participation easily. There are, however, acceptable reasons for doing this.

Warranted concealment of the research purpose

(1) There might be an ethical dilemma between the demand to disclose all relevant information prior to asking for consent and the demand to avoid any unnecessary embarrassment of addressees. Foreseeable embarrassments caused by informing about the purpose of the study have to be avoided. The information may be transmitted indirectly by disclosing why a person (or a family) was selected for participation or by explaining the function of measurements and questions used in the study. Every implicit or explicit suggestion of the existence of a risk factor is very delicate

under ethical points of view as long as it does not help to prevent negative development. Aside from existing risk factors there are many more information that bear the risk of causing discomfort, negative feelings, and problems, for instance, unknown or repressed information that could impair self-esteem as well as the view of one's social context, or one's development such as being an adoptee, being genetically a member of an ethnic minority, being the child of a criminal parent, etc.

(2) There might be a dilemma between a demand of the ethic of science and a demand of the ethic of research.³⁾ The ethic of science demands to avoid flaws impairing the validity of the study including the representative nature of the research sample. The ethic of research demands complete information of participants that might end up in a very selective sample. This is an ethical dilemma. There are several reasons why informing participants about the true purpose could reduce the scientific validity of the study. Whether induced anxieties would lead to refuse participation, or whether they would motivate respondents to participate - hoping to prevent risks - the outcome would be a selective sample instead of a representative one. Additionally, expectations concerning the benefits of a participation may interact with the risk factors (and possibly reduce their effects). This would diminish the generalizability of results. Target group and control group should ideally not differ in the motivation of participation and in the attitudes toward the study (according to the methodological assumption *ceteris distributionibus paribus*). That is the reason for informing the target group and the control group in the same way. Informing about the true purpose (investigation of a risk factor) would, however, be differently received by members of the target group and members of the control group. This would cause another confounding between the risk factor under study and the group membership which again would jeopardize the validity of the study.

(3) One last argument for concealment shall be mentioned. The research purpose is mirrored in the selection of samples: It makes a difference whether potential participants are contacted as individuals or as members of an interesting subpopulation, for instance, as blacks to be compared with whites, as homosexuals to be compared with heterosexual, as conservatives to be compared with socialists, as women to be compared with men, and so forth. Participants might behave differently according to whether they had been contacted as individuals or as representatives of a subpopulation. Depending on the information about the purpose different components of self-image will become salient, tendencies of distancing from outgroups, defensive tendencies, tendencies of palliation, and so forth will be aroused. It might be motivating for special efforts and possibly mean a testing of the limits if participants are fully informed about the exact purpose of the study. The engaged vegetarian will possibly report on his health or his illnesses in a different way if he believed to have been contacted as an individual or if he had been contacted explicitly as a vegetarian in a comparative study with nonvegetarians.

Schulsinger's project (this volume) about the relationship between psychopathology of a parent and the development of their children gives an example of such ethical dilemmas. Children and adolescents as well as the respective guardians were not informed about the true intent of the study. There are good reasons for concealing the true purpose:

(1) Avoiding anxieties and anxiety-induced disturbances. Independent of the decision whether the contacted person (or family in this case) would have consented to participate or not: The question alone could have induced embarrassments and anxieties that would only have been a

burden and as such not productive in the sense that adequate preventive measures could have been chosen: they - I guess - were not available.

(2) Protecting the validity of research.

(a) If there were more refusals or more consents to participate on account of anxieties induced by informing about the purpose of the study than were randomly expected the sample would not have been representative for the population any more.

(b) If there were consent to participate on account of anxieties - maybe in the hope to minimize the risks of maldevelopment - the participation itself would have been a quasi-intervention that might influence the course of development (in other cases the effects of treatments) simply by the confidence that the participation would be helpful. Possible interactions between the effects of the investigated causal factor (psychopathology of a parent) and effects of the information reduce the validity of the study.

Where is the ethical problem in concealing the purpose of the study? We have arguments that are participant-centered, and we have arguments that are science-centered that both touch the validity of research.

Warranted concealment of assessed or expected risk factors

If indicators were assessed that predict maldevelopment and preventive measures were known and available then it would be the researcher's duty toward the participant to suggest corrective or preventive measures. If participants started these measures they would have to be excluded from the study, they would have to be treated like involuntary drop outs. If drop outs were selective, the validity of the study and the generalizability of the results would be impaired.

A concealment of such information seems to be in order when there are only hypotheses about risk factors or lay theories, and their practical significance (not only the statistical one) has not yet been confirmed empirically: The proportion of false positives will otherwise be extremely high the consequences would be unnecessary fears of many participants and expensive preventive measures the necessity of which is still doubtful.

Concealment of the measurement intention

Full information would include, too, to inform about everything that will be measured. There are different reasons for not doing this that concern the welfare of the participants, their readiness to participate, or the validity of the results.

Many questionnaire studies contain control measures that assess tendencies to give palliating answers: "Lie"-scales, scales of social desirability. If potential subjects were informed about their intent, many of them would probably resentfully refuse to participate. Moreover, the usefulness of such control measures depends on whether or not their function (measurement intention) can be concealed. This is equally true for other measurements: projective measures, objective personality tests, indirect assessment of attitudes and value orientations (e.g., to ask for the attitudes of friends instead of for their own attitudes). In principle, when the data are treated confidentially, and when they are anonymized afterwards, the inclusion of these instruments is not harmful for the participants but it is useful for the validity of the study.

In communication with potential participants it is not necessary to conceal the fact that they will not be informed about the intention of each and every instrument. A common suggestion that knowing the intention of one or the other instrument might interfere with the measurement intention could be considered.

Another reason for concealing the measurement intentions is exemplified by medical and epidemiological projects. Frequently, the number and kind of measures such as chemical and bacteriological analyses of blood and urine samplings, will not be told, in order to avoid having participants ask for diagnostically relevant results of the analyses. This practice becomes an ethical problem when symptoms of illness will be found that could be treated. Starting a medical treatment, however, might imply an exclusion of the participant from the study whereby the validity of the whole study might be impaired.

Suppose that in a longitudinal descriptive study the effects of vitamin pills shall be tested. Many different parameters will be assessed to be able to register multiple effects. If all subjects were identified who have deviant scores and if specially indicated treatments were organized for them, e.g., entailing special diets that interact with the vitamin supply, the generalizability of the results would be drastically limited.

To prevent the illusionary belief of participants to be under steady medical surveillance, participants should be informed that participating in the project does not substitute their regular medical check ups or their usual private health monitoring.

6. The Consent Capacity of Children

An important problem is the consent capacity of children. There are age limits for entering legal contracts. It is open to question at what age children and adolescents are first allowed to give formal consent. This implies that formal consent has to be given by parents or institutional guardians (proxy consent). The National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research, however, suggested that children at and above the age of

seven should be asked to give "assent" (Cooke, 1982). This recommendation should only be ignored if an intervention is clearly in the best interest of the children (and, of course, proxy consent is given by a parent or the guardian). I agree with Keith-Spiegel (1984), however, who pointed to several ambiguities in anticipating benefits through participating in research:

- Research cannot guarantee beneficial results in advance. Contrary to medical or psychological intervention practice the goal in research is the evaluation of intervention procedures not the use of the ones that are still in the testing stage.

- There might be some benefit attributed to every experience such as feeling good about contributing to science, enjoying the experimental procedure, learning something new about the self or the world, learning how to cope with stressors, and so forth. Thus, every experience might in fact contribute to the process of the child's growing up. This argument may be used as a justification for making a child participate without his/her assent. It is an adequate means for an "accordion morality".

Special ethical issues in research with minors

In research with children, some specific ethical dilemmas are possible that result from the fact that the child is a minor for whom parents or guardians (in the following: parents) have responsibilities and that the child is dependent on the adults. The researchers are aware of this special relationship and they need the parents' consent for having the child participate in the study. This implies that the parents are given all information that are usually given to the participant.

How is there to decide, however, when the parents consent but the child refuses the assent to participate, expressed - depending on mental age - verbally, by emotional-facial expression, by refusing to cooperate, and so forth? Since every coercion is disapproved, one has to respect the child's right to withdraw. Having used persuading measures to secure participation charges the researcher with the responsibility for the participation and its consequences.

How should be decided when there is a conflict of confidentiality? Who is to be warned about observed risks and threats? The child or the parents or someone else? What is to be done when the child discloses confidential information to the researcher that is unknown to the parents implying, however, a risk to the child? Is the researcher allowed to inform the parents? Information of this kind could be deviant behavior (delinquent acts, drug abuse, smoking, drinking alcohol), having sexual contacts, but also being mistreated by a parent, being sexually abused by a relative, and so forth.

There is no absolutely valid specific ethical rule. If ever possible, the researcher should discuss the issue with a board for ethical questions in research. Depending on age, the child might be included in the process of reflection to come to a mutually approved decision of what to do.

7. Justice in Research

Beyond the threats to privacy and autonomy there are multiple strains and stresses participating in research may impose. Let us suppose that an investigation will ultimately be successful and deliver new knowledge that is useful for optimizing individual development, for preventing or

curing disturbances and illness. Many people may profit from research on the costs that participating subjects will encounter.

If the research is merely a byproduct of an ultimate endeavor to help a patient by using a new treatment since nothing else had worked so far, justice will not be threatened. Neither will there be a threat to justice when research is done by evaluating existing practices in medicine, in family education, in schooling, in institutions for the mentally handicapped, and so forth. The "selection" of "participants" in these "treatments" and settings is not done by the researcher who is only assessing and evaluation what happens there. If research is merely descriptive using non-reactive measures, and if there is no intervention and change in usual routines, justice will not be threatened.

But all other kinds of research bear a challenge to justice, even assigning participants to a treatment or to the control group. Even publishing the results afterwards could mean the psychic risk of experiencing injustice: Let us assume the study results in significantly positive effects of the intervention under study, one of the participants, however, had been (randomly) assigned to the control group: Will he feel unjustly deprived? After all, it would be easy for him to imagine that he might have been in the "privileged" treatment group (Mark & Folger, 1984) that might cause negative effects. More probable threats to justice are mentioned above listing possible strains, stresses and costs of participation.

I think, the researcher and the society have to realize and to acknowledge that participants contribute unequally to gains in useful knowledge. Since the present paper is focused on communication with participants, I would like to draw the attention to the contributions of participants who are usually not adequately compensated for their efforts neither in benefits nor in tangible rewards. We should at least communicate to them that we acknowledge their burden and, speaking for the society, we should thank them. Moreover, it might also help if we changed the status of subjects into the status of participants when their efforts and costs in time etc. are gratefully mentioned in publications.

Referring to the introduction section, I would like to suggest that such a "culture" of interaction and communication between researcher and participants implies a professional ethic that will develop in discourses about conflicts with ethical principles and about ethical dilemmas. I really hope that science will be able to avoid legal regulations with all their rigidities and restrictions. The freedom of science is a high value, and it corresponds to the freedom of the "mündigen Bürger" consenting to participate in the process of research. Freedom implies responsibility. Mutual responsibility is the ethical guideline that makes strict legal or law-like regulations superfluous.

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