The "Right Not to Know": A Survey of Patients, Medical Health Care Professionals and the General Population

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Introduction

There is an ongoing debate on how to return incidental findings to patients in routine clinical care and participants in a scientific study, particularly in regard to genetic research. The question whether and how incidental or additional findings should be disclosed to patients or study participants has been elaborated from different perspectives (see Table 1 for an overview). Experts published commentaries, institutions published recommendations and the public opinion towards the return of incidental findings has been examined. The tenor of the discussion suggests that disclosure is the most adequate solution in most cases and that this view is supported by the majority of the population as if it wants to learn their results (Bui et al. 2014; Bollinger et al. 2012). Investigations into attitudes towards incidental findings have repeatedly found that the majority of people surveyed are in favor of full disclosure of results, including risk information that has no potential for clinical prevention or intervention. Thus the possibility to 'opt-out' and the related concept of the 'right not to know' faded into the background. However, the present study examined the population´s attitude towards the disclosure of incidental findings, the right not to know and went a step further by analyzing factors that make people more likely to use the right not to know. The results showed why it still makes sense to attach value to 'the right not to know'.

Table 1: Arguments for and against the disclosure of incidental findings (IF) (Lohn et al, 2014, p.464)

Pros	Cons
Beneficence, Possibilities of Treatment/Prevention, 'duty to warn'	Potential discrimination, stigmatization, and psychological harm
Individual´s right to her/his genetic information	The costs of interpretation and follow-ups
Research context: Providing IF to participants supports reciprocity and public engagement in genetic research	Lack of necessary expertise to interpret IF adequately
	The individual´s 'right not to know'

Methods and Material

This survey examined the attitudes of the German population towards incidental findings, genome sequencing, physician-patients-relation, and the involvement of third parties (for a detailed description of the sections see Table 2). The sample comprised professionals from the health care system, people suffering from somatic disorders and their relatives, participants of genetic counseling sessions as well as members of the general population. Furthermore, the study analyzed the effect of various demographic variables (e.g. gender, religion, educational level, healthcare-related job) on these attitudes.

Data were collected by the means of a 52-item questionnaire. The survey was conducted via paper-pen (N=335) and via online-version (N=188). The paper version was mainly handed out in the context of the hospital attached to University of Goettingen. The survey link was published via newsletters and homepages (e.g. German Association for Bipolar Disorder (DGBS), The German Association for Psychiatry, Psychotherapy and Psychosomatics (DGPPN), University Hospital Goettingen). Data were collected from June 2014 until November 2014.

Table 2: Sections of the questionnaire

Sections	Focus of interest
Demography	Age, sex, family background, religion, educational level
Attitudes towards the 'right to know' &'right not to know' (Disclosure)	Anticipated consequences Differentiation between risk & diagnosis, Openness towards genetic testing Disease conditions (kind, severity, age of exacerbation) Preferred information & preferred process of disclosure
Physician´s duty to help & patient´s right of self-determination	Confidence in medicine e.g. physician´s refusal to accept patient´s initial decision
Transfer of information to others	Relatives, children, partner, institutions (e.g. insurance companies)

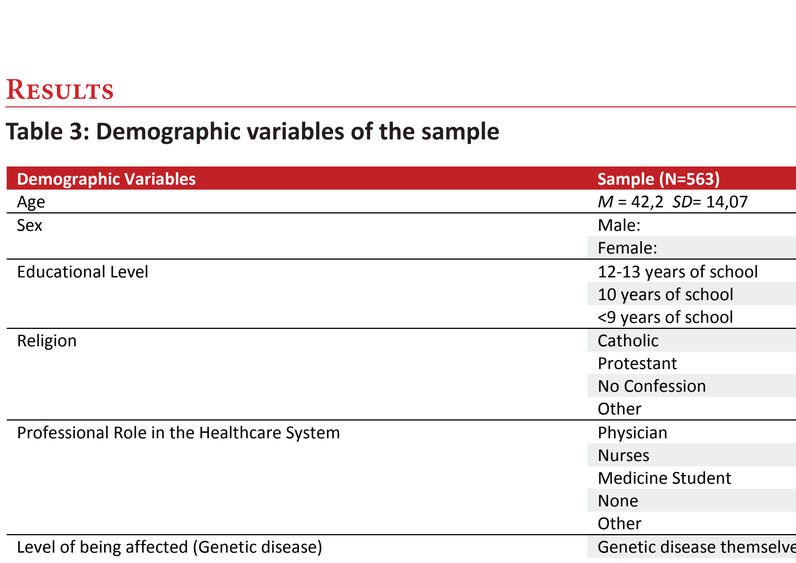
Results

Table 3: Demographic variables of the sample

Demographic Variables	Sample (N=563)	
Age	*M* = 42,2 *SD*= 14,07	
Sex	Male:	30,5 % (N=148)
	Female:	69,5 % (N= 338)
Educational Level	12-13 years of school	45,6 %
	10 years of school	25,4 %
	<9 years of school	13, 7%
Religion	Catholic	22,6 % (N=115)
	Protestant	40,6 % (N=206)
	No Confession	31,9 % (N=162)
	Other	4,9 % (N=25)
Professional Role in the Healthcare System	Physician	7,2 % (N=35)
	Nurses	4,3 % (N=21)
	Medicine Student	2,5 % (N=12)
	None	65,2 % (N=316)
	Other	20,8 % (N=101)
Level of being affected (Genetic disease)	Genetic disease themselves	13,7 % (N=72)
	Affected family members	23,5 % (N=122)
	themselves & family members	11 % (N=58)
	Not affected	51,2 % (N=268)

Descriptive Results

The majority (~80%) prefers disclosure in case of the occurrence of an incidental finding, but the wish is influenced by the specific conditions of the finding (differentiation between risk/diagnosis, clinical utility). Although the 'wish to know' dominates, the majority also anticipates negative consequences (societal discrimination: 50,8 % (N=256); emotional distress: 75,2 % (N=378)). Participants emphasize their right of self-determination (67,7% (N=337)), but in exceptional cases, a substantial number (59,7 % (N=298)) would agree if the physician ignores their initial decision. The transfer of information to institutions (e.g. insurance companies) is refused by 92% (N=460). The wish to receive information decreased due to the presented scenario (Graphic 1).



Statistics

After examining the general attitude of the population a closer look at the different groups revealed interesting differences.

1. Educational Level

People with a higher educational level (>12 years of education)cshowed a more critical attitude towards genetic testing (including transfer of information), were more reflective and differentiated better between the different scenarios and also were more likely to make use of the right not to know/reject information. Table 4 shows selective items that make the differences visible.

Table 4: Significant Items: Factor ‚Educational Level'

Item	Significance
There is a simple and reasonably priced option to be tested for your risk for more than 250 genetic disorders. Would you get yourself tested?	***p* = .000** $\chi 2$ (2, N = 483) = 16.21
Would you want to know already before the birth whether your child has a genetic risk for a genetic disorder?	***p* = .014** $\chi 2$ (2, N = 483) = 8.6
Should people who have jobs with special responsibility (e.g. pilots) be tested for certain genetic risks?	***p* = .000** $\chi 2$ (2, N = 487) = 30.75
Should various insurances (life insurance, occupational disability insurance, disability insurance, long-term care insurance) have the right to have their applicants/members tested for a genetic risk, to allow them perhaps to adjust the contribution amount according to the determined risk?	***p* = .000** $\chi 2$ (2, N = 482) = 24.11

2. Professional role in the healthcare system

People with a professional role in the healthcare system (physicians; medical students) showed a more critical attitude towards genetic testing (including transfer of information), were more likely to make use of the right not to know/reject information, were more likely to emphasize the patient´s autonomy (Table 5).

Table 5: Significant Items: Factor ‚Professional Role in the healthcare system'

Item	Significance
Genetic tests can result in people who are found to have a genetic disorder being socially discriminated or excluded from society.	***p* = .0007** $\chi 2$ (16, N = 471) = 33.3
I want to know about any disease I have that is found incidentally.	***p* = .005** $\chi 2$ (12, N = 467) = 28.5
I want to know about any risk I have for a genetic disorder that is found incidentally.	***p* = .002** $\chi 2$ (12, N = 468) = 31.73
There is a simple and reasonably priced option to be tested for your risk for more than 250 genetic disorders. Would you get yourself tested?	***p* = .015** $\chi 2$ (16, N = 469) = 30.53
My physician should know all my genetic findings and decide on the basis of his professional knowledge which he tells me about and which he doesn't tell me about.	***p* = .016** $\chi 2$ (16, N = 466) = 29.7

3. Religion

Religious people (Catholics; Protestants) were more likely to emphasize the physician´s duty of care and were more likely to trust the physician´s decisions than people without a religion (Table 6).

Table 6: Significant Items: Factor ‚Religion'

Item	Significance
My physician should know all my genetic findings and decide on the basis of his professional knowledge which he tells me about and which he doesn't tell me about.	***p* = .000** $\chi 2$ (4, N = 463) = 22.14
Which of the following do you think outweighs the other: - The physician's duty of care towards you as a patient or - your right to self-determination, to decide yourself what you want to know about yourself and what not?	***p* = .006** $\chi 2$ (4, N = 465) = 14.6

Discussion

The majority of participants were interested in receiving information about incidental findings, but their wish to know varied depending on the scenario. Our participants' attitudes towards genetic testing, incidental findings (including the right not to know) were influenced by the level of education, religion and the professional role in the healthcare system whereas 'being affected/being a patient' had no influence.

The attitude towards and perception of the 'right not to know' seems to be affected by the way we ask people e.g. if they are asked for an abstract concept or if they are confronted with concrete scenarios, that include examples (e.g. Breast cancer). There is an overwhelming majority of 88,4 % that stated that they want to know everything, when being asked in an abstract way, but when it comes to concrete scenarios including various features (e.g. consequences of the disease), 12,2 % of these people changed their minds and refused to get this information.

The study shows that we will not find one general attitude about these topics in the population, even though it might seem like this at first glance. Inter- and intrapersonal factors and the way questions are posed, can lead to different opinions and result in different decisions. As a conclusion these factors should be examined systematically and then be considered in clinical practice for example the verbalization of informed consent.

References

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Disclosure

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