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RESEARCH ARTICLE

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Attitudes toward the right to autonomous decision-making in psychiatric genetic testing: Controversial and context-dependent

Jana Strohmaier[1] | Stephanie H. Witt[1] | Josef Frank[1] | Noemi Lemme[1] | Laura Flatau[2] | Fabian Streit[1] | Jerome C. Foo[1] | Markus Reitt[3] | Dan Rujescu[4,5] | Thomas G. Schulze[2,3] | Dirk Lanzerath[6] | Franciska Illes[7] | Franziska Degenhardt[8,9] | Marcella Rietschel[1]

[1]Department of Genetic Epidemiology in Psychiatry, Central Institute of Mental Health, Medical Faculty Mannheim, University of Heidelberg, Mannheim, Germany

[2]Institute of Psychiatric Phenomics and Genomics, Ludwig-Maximilians-University, Munich, Germany

[3]Section of Psychiatric Genetics, Department of Psychiatry and Psychotherapy, University Medical Center, Georg-August-University, Göttingen, Germany

[4]Department of Psychiatry, Psychotherapy and Psychosomatics, Martin-Luther-University Halle-Wittenberg, Halle, Germany

[5]Department of Psychiatry, University of Munich (LMU), Munich, Germany

[6]German Reference Centre for Ethics in the Life Sciences (DRZE), Bonn, Germany

[7]Department of Psychiatry, Ruhr University Bochum, LWL-University Hospital, Bochum, Germany

[8]Institute of Human Genetics, University of Bonn, Bonn, Germany

[9]Department of Genomics, Life & Brain Center, University of Bonn, Bonn, Germany

Correspondence
Marcella Rietschel, Department of Genetic Epidemiology in Psychiatry, Central Institute of Mental Health, Medical Faculty Mannheim, University of Heidelberg, Mannheim 68159, Germany.
Email: marcella.rietschel@zi-mannheim.de

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Recent breakthroughs in psychiatric genetics have identified genetic risk factors of yet unknown clinical value. A main ethical principal in the context of psychiatric research as well as future clinical genetic testing is the respect for a person's autonomy to decide whether to undergo genetic testing, and whom to grant access to genetic data. However, experience within the psychiatric genetic research setting has indicated controversies surrounding attitudes toward this ethical principal. This study aimed to explore attitudes concerning the right of individuals to self-determine testing and disclosure of results, and to determine whether these attitudes are context-dependent, that is, not directly related to the test result but rather to specific circumstances. *N* = 160 individuals with major depression or bipolar disorder and *n* = 29 relatives of individuals with either illness completed an online-questionnaire assessing attitudes toward genetic testing, genetic research, disclosure of results, incidental findings, and access to psychiatric genetic test results. Generally, the right of the person's autonomy was considered very important, but attitudes varied. For example, half of those who considered that children should have the right to refuse psychiatric genetic testing even against their parents' will, also state that they should be tested upon their parents' wishes. Also, the majority of respondents considered the physician entitled to disregard their stated wishes concerning the disclosure of incidental findings in case of good treatment options. Thus, researchers and clinicians must be aware that attitudes toward psychiatric genetic testing are often mutable and should discuss these prior to testing.

Jana Strohmaier, Stephanie H. Witt, Franziska Degenhardt, and Marcella Rietschel authors are shared first/last authorship.

KEYWORDS
ambivalence, *privacy*, psychiatric genetic testing, right to *self-determination*

1 | INTRODUCTION

Breakthroughs in the identification of the genetic risk factors for psychiatric illness suggest that in the foreseeable future, genetic testing might become feasible and introduced in clinical practice to improve the diagnostic process (Smoller et al., 2018; Sullivan et al., 2018). Psychiatric disorders are complex genetic disorders with many common variants each conferring relatively small effects. In rare cases, psychiatric disorders are largely explainable by single mutations or copy number variations (CNVs). Diagnostic and predictive tests have been established for single mutations causing neurodevelopmental and neurodegenerative disorders often co-manifesting with psychiatric symptoms (e.g., phenylketonuria, Huntington disease). Analysis of CNVs is used for diagnostic workup for autism spectrum disorders, developmental delay, and intellectual disability in children and in selected cases, in adults with major mental disorders. Testing the burden of the cumulative effects of common risk variants is in principle possible and already marketed (e.g., https://staging.geneplaza.com/app-store/68/preview; Plomin & von Stumm, 2018), albeit not recommended yet for clinical use (International Society of Psychiatric Genetics, 2019; https://ispg.net/genetic-testing-statement). The effective translation of the abovementioned findings in clinical practice will require a full evaluation, which includes several requirements (Haddow & Palomaki, 2004; International Society of Psychiatric Genetics, 2019; Marzuillo, De Vito, D'Andrea, Rosso, & Villari, 2014); today, evaluation frameworks of genetic testing mainly focus on analytic and clinical validity, clinical utility, and even economic aspects, but less on ethical, legal, and social implications (ELSI), the context of implementation, and viewpoints of consumers (D'Andrea et al., 2016; D'Andrea, Marzuillo, Pelone, De Vito, & Villari, 2015; Di Marco et al., 2018; Pitini et al., 2018). This is likely due to concerns about systematic ethical examination in ELSI research (Walker & Morrissey, 2014). It should be kept in mind that genetic attributions are often overestimated, even when the genetic data are weak (Dar-Nimrod & Heine, 2011).

ELSI evaluation before the implementation of a given genetic test in the health care setting is crucial to anticipate possible negative implications for the test person, the relatives of the test person, physicians, and society at large (EC Expert Group, 2004). It becomes even more critical in psychiatry, where ELSI analysis is complicated by the complex genetic architecture of mental illnesses, the biologically imprecise concepts of mental illnesses and health (Anttila et al., 2018), and the social stigma associated with mental disorders (Appelbaum & Benston, 2017; Byrne, 2001; Szasz, 1960). These issues are particularly complex in the case of individuals who are unable to provide informed consent, for example, legal minors (Burke, Evans, & Jarvik, 2014).

While previous literature has consistently reported very high levels of approval for psychiatric genetic research and testing, it has also been shown that individuals have concerns about autonomy, privacy, discrimination, and coping emotionally with test results (e.g., Austin, Smith, & Honer, 2006; Bui, Anderson, Kassem, & McMahon, 2014; Coors, 2005; DeLisi & Bertisch, 2006; Illes, 2008; Jones, Scourfield, McCandless, & Craddock, 2002; Klitzman et al., 2013; Lawrence & Appelbaum, 2011; Meiser et al., 2008; Meiser, Mitchell, McGirr, Van Herten, & Schofield, 2005; Middleton et al., 2016; Roberts, Tsungmey, Kim, & Hantke, 2018; Salm et al., 2014; Smith, Sapers, Reus, & Freimer, 1996; Sundby et al., 2017; Trippitelli, Jamison, Folstein, Bartko, & DePaulo, 1998; Wilde, Meiser, Mitchell, Hadzi-Pavlovic, & Schofield, 2011; Wilhelm et al., 2009; Yu, Crouch, Jamal, Bamshad, & Tabor, 2014). It has also been reported that further information about potential positive and negative implications decreases interest in being tested (Illes et al., 2006; Wilde, Meiser, Mitchell, & Schofield, 2010). Genetics researchers are the most hesitant to endorse psychiatric genetic testing, followed by psychiatrists, the general population, and patients/relatives (DeLisi & Bertisch, 2006; Illes, 2008; Sundby et al., 2017), an observation which indicates that attitudes toward psychiatric genetic testing are dependent upon background or degree of expert knowledge. Each group may foresee problems and may have insights or perspectives which are not immediately apparent to other groups. Furthermore, controversies with respect to the right of autonomous decision-making also exist within groups, and even single individuals make seemingly contradicting statements: for example, a large proportion of individuals who are strictly against employers being informed about genetic test results favor testing in individuals with positions of particular responsibility (Illes, 2008).

The aim of the present study was to examine whether the controversies surrounding the right for autonomous decision-making and privacy can be confirmed, and to investigate context-dependent factors, that is, the specific group under consideration (e.g., minors) or specific circumstances which had not been taken into consideration before (such as the potential relevance of the finding for life-planning). A specific focus was placed on addressing questions which arise in the research context.

2 | MATERIALS AND METHODS

2.1 | Ethics statement

The study was performed within the IMAGEMEND project (http://www.imagemend.eu/the-imagemend-study-3/the-imagemend-study). The study was approved by the ethics committee of the University of Heidelberg, Germany and all study procedures were conducted in accordance with the Declaration of Helsinki (World Medical Association, 2013).

2.2 | Sample description

The cohort comprises individuals with a self-reported history of major depression or bipolar disorder, n = 160; and relatives of individuals with major depression or bipolar disorder, who were not necessarily participants of the present study, n = 29. All participants were members of the German Society for Bipolar Disorder (DGBS). The DGBS is an

independent trialogue association of individuals with bipolar disorder and/or major depression, relatives, and mental health professionals. The major aim of the health care policy of the DGPS is to promote the needs of individuals with bipolar disorder and major depression in public and public health care policy. In November 2013 all members (members 2013: 1413) were informed via their website (https://dgbs.de/) about the possibility to participate in our survey by using a predefined internet link. The link remained valid until November 2015 (members 2015: 1694). No inclusion or exclusion criteria were defined, participation was anonymous, no reminders were sent, and participants were invited to ask questions or give feedback in order to improve future studies. Analysis was started in December 2015.

2.3 | Online questionnaire

The present study was performed using a German language questionnaire designed by the authors (see Supporting Information). This questionnaire was augmented by the inclusion of items from a survey our group conducted in 2003 (Illes, 2008); for details see analyses and presentation of results section below), and other investigations performed by our group and previous authors (Flatau et al., 2018). The questionnaire was designed for use in diverse research contexts (e.g., molecular genetic research or imaging research), and populations (e.g., psychiatric patients, relatives, psychiatrists, and members of the general public), and therefore covers a wide range of topics of relevance to psychiatric genetic research and psychiatric genetic testing.

The questionnaire is subdivided into 11 sections. These sections concern: (a) presentation of general information about genetic research, and diagnostic and predictive testing for psychiatric illness; (b) personal data (e.g., age, sex, profession, religion), n = 9 items; (c) respondent's own personal level of experience with psychiatric disorders, n = 6 items; (d) respondent's own knowledge concerning the causes of, and courses of, psychiatric disorders, n = 3 items; (e) attitudes toward genetic testing, n = 24 items; (f) attitudes toward genetic research, n = 10 items; (g) attitudes toward the disclosure of results and incidental findings identified in the research context, n = 30 items; (h) the respondent's own evaluation of the consequences of psychiatric genetic research to them personally, to affected persons, and society, n = 7 items; (i) access by others to the results of a psychiatric genetic test, n = 8 items; (j) attitudes toward prenatal genetic testing, n = 17 items; (k) the respondent's willingness to be re-contacted by the research team, n = 1 item. The questionnaire thus comprises 115 items.

Each subsection commences with background information, which the respondent is instructed to read before answering the respective subsection items.

Each item is rated according to a six point scale (1 = strongly disagree, 2 = disagree, 3 = tend to disagree, 4 = tend to agree, 5 = agree, 6 = strongly agree).

The present analyses were based on a subset of data from the following four sections only: attitudes toward genetic testing; attitudes toward genetic research; attitudes toward the disclosure of results and incidental findings identified in the research context; and access by others to the results of a psychiatric genetic test. An English translation of these selected items, as well as the full-length German language questionnaire from 2015, is provided in Supporting Information.

2.4 | Analyses and presentation of results

In addition to the 1–6 rating for each item, responses were dichotomized by grouping answer options 1–3 and 4–6, and were shown as percentages. The percentages provided in the results section and in the Supporting Information refer to these dichotomized values. The respective item number from the 2015 online German language questionnaire (see Supporting Information) is shown in brackets. Graphical presentations of responses, including the total numbers of responses for each rating on the six-point scale, are shown in Supporting Information. Detailed description of and figures depicting frequencies of statements of the 2015 and 2003 surveys are also provided in Supporting Information. Answers from the 2003 survey are also displayed to allow for comparisons with the present study. As the 2003 study represents the largest survey in this field of research so far, it enables the examination of whether patterns of answers differ/have changed in the 2015 survey. The 2003 survey comprised 3,077 individuals assessed in a representative way from the general population and 1,736 individuals from several groups of specific interest, including 313 patients, 252 relatives, and 118 psychiatrists—for details see Supporting Information (Illes, 2008). Differences within and between the groups from the 2015 and 2003 surveys were tested using the χ^2 test uniformly based on a binarized version of the response scale (agreement vs. dis-agreement). Kendall rank based correlation (τ), which takes into account the clearly non-normal distribution of response data, was used to test for correlations between selected statements. Correlations were based on full six-level-scale of items were available.

3 | RESULTS

3.1 | Sample characteristics

The demographics of the cohort are shown in Table 1.

3.2 | Comparisons between the 2015 and 2003 surveys

Attitudes of patients and relatives of the 2015 survey, and of patients, relatives, psychiatrists and the general population of the 2003 survey, are shown in Figures 1–3 and Supporting Information Figures S1–S53, and correlations between different attitudes are shown in Table 2.

p-values for significant differences between the 2015 and 2003 surveys are depicted in Figure S54. Given the large number of participants the 2003 survey most differences in dichotomized agreement versus disagreement between the 2015 and 2003 studies larger than >2% reached nominal statistical significance ($p < 0.05$).

3.3 | Attitudes toward psychiatric genetic research and testing in general in the 2015 survey

Of the 189 respondents, 8% and 7% were against the identification of genes responsible for the development of mental illnesses (6.1) and of somatic disorders (e.g., cardiac disorders, diabetes mellitus II, cancer) (6.2), respectively. Ninety-one percent approved of the statement that one of the goals of psychiatric genetic research is to develop new drugs

TABLE 1 Demographic characteristics of assessed samples

Year of assessment	Respondent category	*n*[a]	Male-%	Female-%	Age mean (*SD*)
2003	Patients/relatives	568	44.0	56.0	27.4 (15.6)
2003	Patients	316	48.7	51.3	26.5 (14.5)
2003	Relatives	252	38.1	61.9	28.6 (17.0)
2003	Psychiatrists	118	53.4	46.6	20.1 (8.4)
2003	General population	3,077	40.8	59.2	24.6 (15.7)
2015	Patients/relatives	189	25.4	74.6	45.4 (12.4)
2015	Patients	160	27.5	72.5	44.6 (11.9)
2015	Relatives	29	13.8	86.2	49.9 (14.3)

[a]Abbreviations. *n*: number of participants; *SD*: standard deviation.

(6.3). Fourteen percent expressed the opinion that the money spent on psychiatric genetic research should be invested instead in other fields of medical research (6.4). The distribution of responses was comparable to that found in patients and relatives in the 2003 population-based survey (see Supporting Information Figures S16–S19).

Seventy-five percent of respondents stated that if their physician offered them such a test tomorrow, they would agree to undergo a psychiatric genetic examination (5.1) in order to learn more about their level of risk (5.2).

Eighty-seven percent responded that a high predictive certainty was a prerequisite for such a test (5.20). More than 50% expressed the opinion that such a test should only be carried out when the illness in question is preventable (70%; 5.18)/treatable (59%; 5.19)/or severe (62%; 5.21).

3.4 | Autonomy to decide whether or not to undergo psychiatric genetic testing and to grant access to results of a psychiatric genetic test

Almost all respondents disagreed (most of them very strongly) with the statement that psychiatric genetic tests should be permitted without the knowledge of the test person (94%; 5.8) and 71% agreed with the statement that children should be able to refuse psychiatric genetic investigation (even against their parents' wishes; 5.10, see Figure 2). On the other hand, at the same time, 56% held the opinion that children/teenagers under 18 should be examined for a genetic risk of developing a mental disease if their parents' wished so, even without their own consent (5.9). When the respondents were asked whether they would—as a parent—have their child tested for the risk

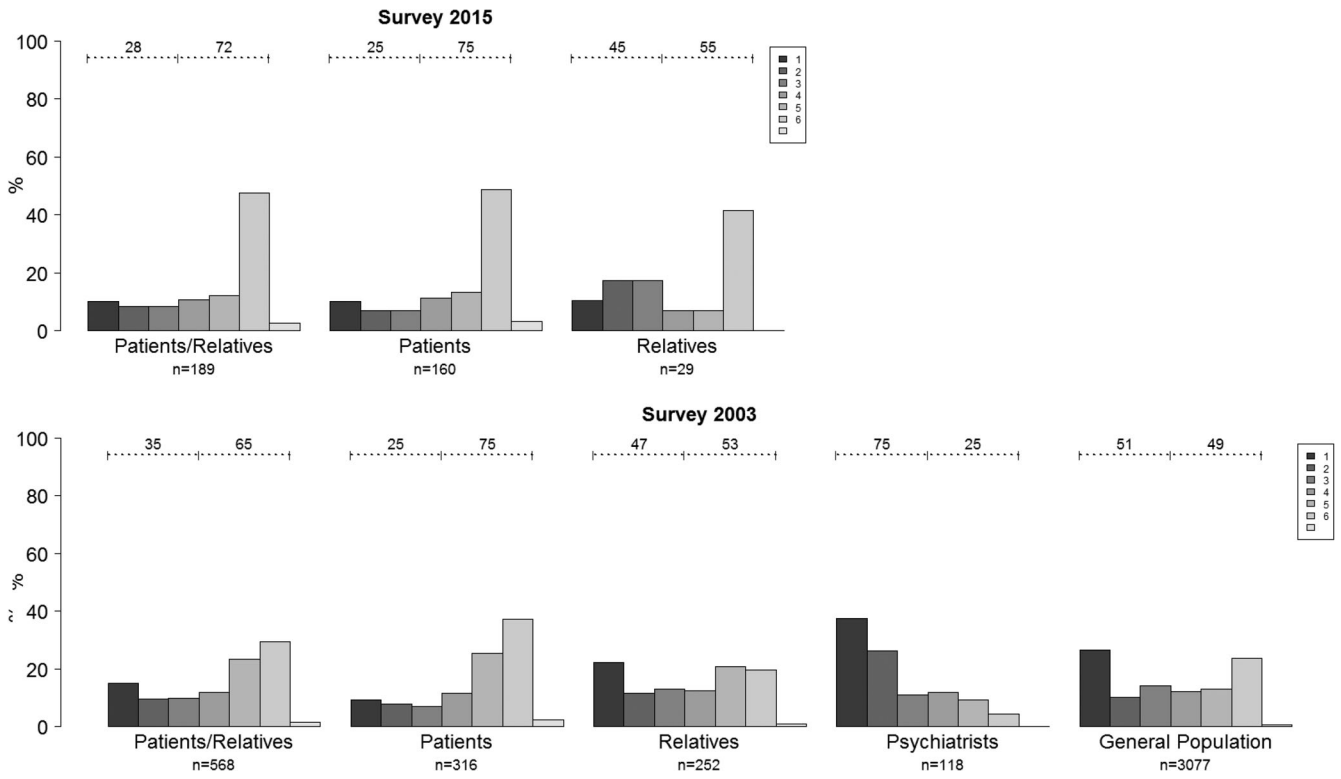

FIGURE 1 Degree of (dis-)agreement with the statement: "I would undergo genetic investigation in order to be able to evaluate the risk for myself." (Dis-)agreement is presented for the 2015 (upper panel) and 2003 survey (lower panel). Group numbers 1–6 denote degree of (dis-) agreement with statement above (1: "strongly disagree", …, 6: "strongly agree"). Bar heights indicate percentages for each of the options and missing answers (empty category, missing). Numbers above the dashed lines denote dichotomized agreement/disagreement percentages, after exclusion of respondents with missing answers. n = number of respondents

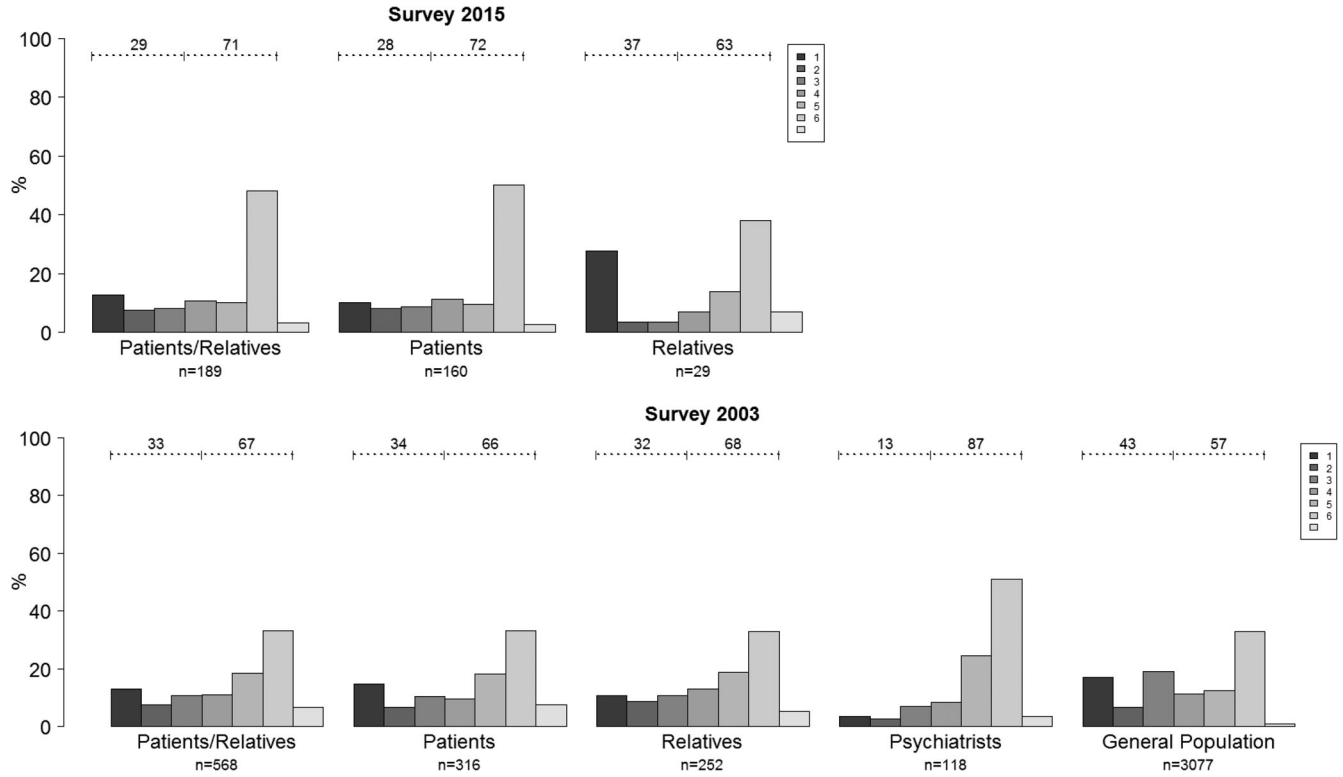

FIGURE 2 Degree of (dis-)agreement with the statement: "Children should be able to refuse to undergo psychiatric genetic investigation (even against their parents' wish)." (Dis-)agreement is presented for the 2015 (upper panel) and 2003 survey (lower panel). Group numbers 1–6 denote degree of (dis-)agreement with statement above (1: "strongly disagree", …, 6: "strongly agree"). Bar heights indicate percentages for each of the options and missing answers (empty category, missing). Numbers above the dashed lines denote dichotomized agreement/disagreement percentages, after exclusion of respondents with missing answers. n = number of respondents

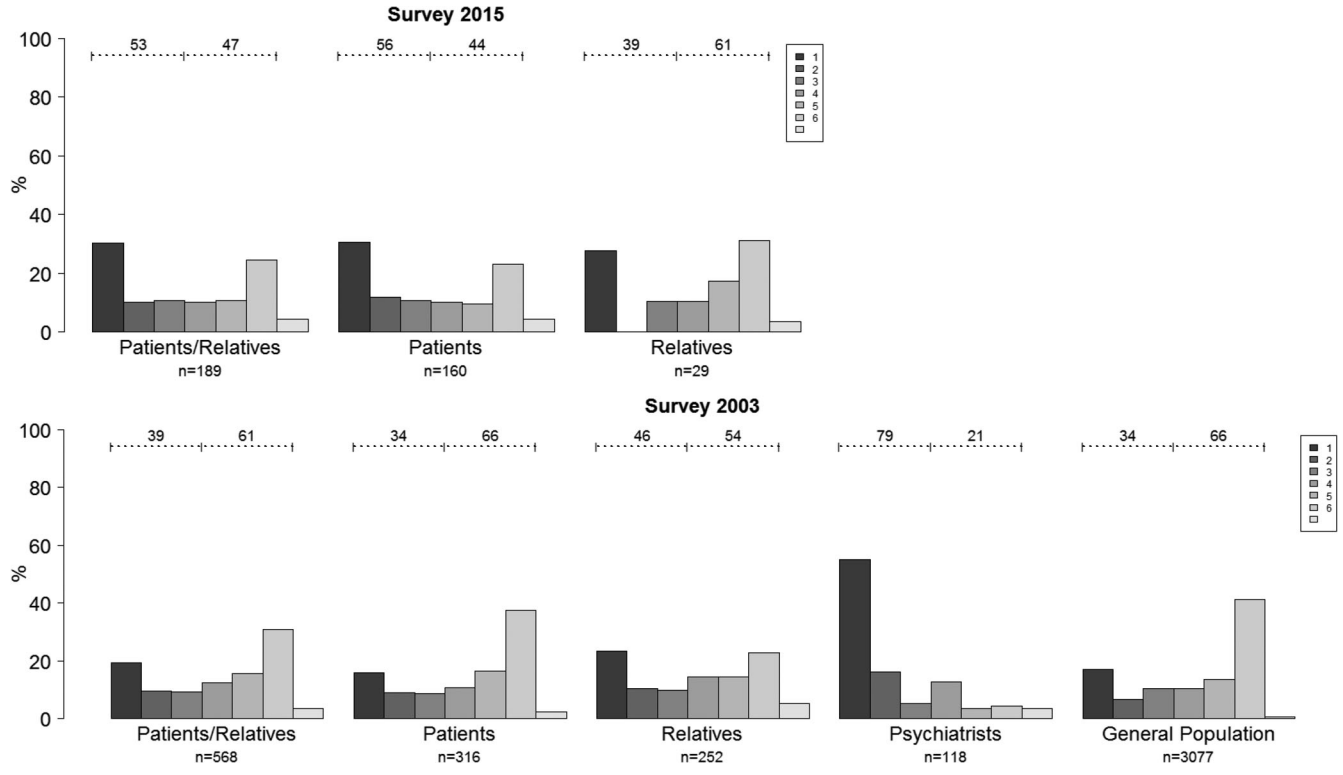

FIGURE 3 Degree of (dis-)agreement with the statement: "People with particularly responsible jobs (e.g. pilots) should undergo psychiatric genetic examination." (Dis-)agreement is presented for the 2015 (upper panel) and 2003 survey (lower panel). Group numbers 1–6 denote degree of (dis-)agreement with statement above (1: "strongly disagree", …, 6: "strongly agree"). Bar heights indicate percentages for each of the options and missing answers (empty category, missing). Numbers above the dashed lines denote dichotomized agreement/disagreement percentages, after exclusion of respondents with missing answers. n = number of respondents

TABLE 2 Pairwise correlations between selected items of surveys and conditional agreement with these items

Year	#A[a]	Shorttext A[b]	#B[c]	Shorttext B[d]	Tau[e]	Pval[f]	Logp[g]	pb_na[h]	pb_a[i]	pa_nb[j]	pa_b[k]	Counts[l]
2015	5.9	Allow testing children upon parents wish	5.10	Children may refuse	−0.34	1.0E−08	8.0	82	62	74	50	14,39,64,65
2003	5.9	Allow testing children upon parents wish	5.10	Children may refuse	−0.32	1.8E−15	14.8	79	44	59	23	68,96,258,75
2015	5.10	Children may refuse	5.11	Would test child for T2D	−0.15	1.5E−02	1.8	58	48	74	65	22,63,31,58
2003	5.10	Children may refuse	5.11	Would test child for T2D	−0.10	3.9E−03	2.4	69	58	73	63	53,146,120,204
2015	5.10	Children may refuse	5.12	Would test child for SCZ	−0.23	2.0E−04	3.7	62	46	77	63	20,66,33,57
2003	5.10	Children may refuse	5.12	Would test child for SCZ	−0.21	4.3E−09	8.4	63	44	75	58	63,190,108,150
2015	5.10	Children may refuse	5.13	Would test child for MD	−0.17	6.0E−03	2.2	70	61	75	68	16,49,37,77
2003	5.10	Children may refuse	5.13	Would test child for MD	−0.22	7.2E−10	9.1	67	46	76	58	57,184,117,159
2015	5.10	Children may refuse	5.14	Would test child for skin cancer	−0.17	6.2E−03	2.2	73	57	79	65	14,54,38,71
2003	5.10	Children may refuse	5.14	Would test child for skin cancer	−0.11	2.3E−03	2.6	73	63	73	63	47,128,128,220
2015	5.10	Children may refuse	5.15	Would test child for Alz. Dementia	−0.16	8.9E−03	2.1	58	50	73	67	22,61,30,61
2003	5.10	Children may refuse	5.15	Would test child for Alz. Dementia	−0.15	3.0E−05	4.5	59	43	74	59	71,198,103,148
2015	6.1	Against identification of psych risk genes	6.2	Generally against identification of risk genes	0.80	<2.2E−16	>16.3	2	60	3	75	166,6,3,9
2015	6.1	Against identification of psych risk genes	6.3	Approve goal to develop new drugs	−0.39	4.7E−09	8.3	92	79	19	7	13,3,154,11
2003	6.1	Against identification of psych risk genes	6.3	Approve goal to develop new drugs	−0.44	<2.2E−16	>16.3	97	76	41	7	17,12,488,39
2015	6.1	Against identification of psych risk genes	6.4	Better invest money otherwise	0.36	7.7E−08	7.1	10	54	4	29	148,6,17,7
2003	6.1	Against identification of psych risk genes	6.4	Better invest money otherwise	0.39	<2.2E−16	>16.3	7	42	6	39	459,29,33,21
2015	6.6	Trust in researchers	7.23	Prefer self determination over physicians duty of care	−0.19	6.5E−03	2.2	78	55	79	56	13,48,46,59

[a]Item number of first variable in association test.
[b]Short version of first variable in association test.
[c]Item number of second variable in association test.
[d]Short version of second variable in association test.
[e]Kendall rank based correlation.
[f]*p*-value of test for deviation of correlation from 0.
[g]−log10(*p*-value);
[h]Probability in % of agreeing to Statement B under condition of disagreeing with Statement A.
[i]Probability in % of agreeing to Statement B under condition of agreeing to Statement A.
[j]Probability in % of agreeing to Statement A under condition of disagreeing with Statement B.
[k]Probability in % of agreeing to Statement A under condition of agreeing to Statement B.
[l]Cell counts for frequency table in following order: Not(A) and Not(B), A and Not(B), Not(A) and B, A and B.

of certain specified diseases a total of 51%–64% of respondents stated that they would have their child tested for some of the specified diseases. In ascending order of magnitude, the diseases they would test for if possible were: diabetes mellitus II 51% (5.11), schizophrenia 51% (5.12), Alzheimer´s disease 52% (5.15), skin cancer 61% (5.14), and major depression 64% (5.13).

The majority (94%) of the respondents agreed with the statement that the results of a psychiatric genetic test should be disclosed to the test person only (9.7). 65% of respondents were opposed to the automatic forwarding of psychiatric genetic test results to the general practitioner (9.2). A high level of disagreement was also found for the statement that the following bodies should be allowed to request psychiatric genetic information: employers (98%) (9.3), health insurance providers (94%) (9.4), and life insurance providers (97%; 9.5). Furthermore, the majority (93%) disagreed that health authorities should have a right to know if someone has a genetic risk for a mental illness (9.6). However, 47% of respondents endorsed mandatory psychiatric genetic testing in individuals with positions of particular responsibility (e.g., pilots; 9.8; see Figure 3).

3.5 | Being informed about results and incidental findings identified in the research context

Seventy-six percent of respondents stated that they would *always* want to be informed if they were discovered to have increased risk for any disease/illness (7.1). 39%, 43%, 40%, and, 66% of respondents respectively stated that they only want to be informed if the illness in question was treatable (7.2), preventable (7.3), or severe (7.4), or if the test had a high predictive certainty (7.5). A similar response pattern was observed for incidental findings (7.12, 7.7, 7.8, 7.10; see Supporting Information).

Only 24% agreed with the statement that the study physician/their physician should decide on the basis of his/her specialist knowledge which genetic findings are disclosed (7.18). Furthermore, 93% of respondents disagreed with the statement that the study physician/their physician was entitled to disregard their wishes concerning the disclosure of incidental findings (7.19). These opinions varied when the statements were placed in different contexts. In 7.20–7.23 the respondents were asked to consider a scenario in which they had previously declined the disclosure of incidental findings. However, the study physician/their physician considered it important to inform them that they had a high risk for an illness for which (a) good treatment options (7.20), (b) good methods of prevention, (7.21), or (c) no treatment options (7.22) were available. The respondents were informed that the study physician/their physician was of the opinion that he/she had both the duty and the right to disclose this finding to them. The level of agreement with options a, b, and c, respectively among respondents was 79%, 81%, and 51%. The respondents were then asked to consider which of the following carried more weight: (a) the duty of the study physician toward them as patients; or (b) their right to determine what they wished to know about themselves and what they did not wish to know about themselves. They were informed that they could also respond that (c) they did not know (7.23). The level of agreement with options a, b, and c among respondents was 32%, 59%, and 9%, respectively.

3.6 | Correlations between statements between 2015 and 2003 surveys

Table 2 shows the correlation between selected statements in the 2015 and 2003 studies and the proportion of respondents who agree/disagree with a given statement and agree/disagree with another selected statement of the 2015 and 2003 studies (responses were dichotomized for presenting proportions of agreement).

4 | DISCUSSION

There has been a rapid pace of progress in the field of psychiatric genetics and research indicates that knowledge will continue to increase. While psychiatric genetic testing is not yet available in routine clinical practice, the associated ELSI need to be analyzed before the implementation of genetic testing (EC Expert Group, 2004). Furthermore there are many ELSI warranting urgent solutions which need to be addressed in research settings (Jarvik et al., 2014; National Academies of Sciences et al., 2018). As participatory genomic research pushes conventional research boundaries toward a more democratizing ethos (Aungst, Fishman, & McGowan, 2017), a major ethical and legal principle to rely on is the right of an individual's autonomous decision (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Researcht, 1979). This includes the right to decide whether or not to undergo testing (Andrews, Fullarton, Holtzman, & Motulsky, 1994), and the right to know, or to not know, specific test results (Abbing, 2003; Andorno, 2004; Andrews et al., 1994; Borry, Shabani, & Howard, 2014; Bui et al., 2014; Fulda & Lykens, 2006; Group, 2004; Wolf, Annas, & Elias, 2013). It also includes the right to be in control of one's own data, that is, to refuse the disclosure of genetic test results to third parties but also to be granted access to them (Mascalzoni, Paradiso, & Hansson, 2014).

To be able to fully exert these rights, individuals should be empowered to understand the scope of possible positive as well as negative implications of genetic findings (such as stigmatization, discrimination at work, problems within the familial/societal context, anxiety, etc). This is a difficult endeavor especially as many research results will be of unknown validity and thus of questionable clinical value for research participants. It has to be assumed that in such a complex area attitudes are ambivalent and affected by many factors such as general attitudes toward psychiatric research and that asking simple questions (e.g., whether individuals want to undergo genetic testing) may not be sufficient to obtain a full picture of the wishes and needs of patients and research participants.

The present study therefore explored attitudes of the respondents themselves as hypothetical test persons, and the attitudes of the respondents toward the rights of others for autonomous decision-making in the context of genetic testing. It furthermore sought to identify how different attitudes were correlated and whether these patterns were stable or had changed over the last decade. A specific focus was placed on (a) testing of children, as they are especially vulnerable, as they cannot consent and (b) on the research situation, as there are no binding rules how to proceed with returning genetic research results to participants.

4.1 | Attitudes toward psychiatric genetic research and testing in general

As in our previous investigation in 2003 and in previous literature on psychiatric genetic research and testing (Bui et al., 2014; Laegsgaard, Kristensen, & Mors, 2009; Lawrence & Appelbaum, 2011; Middleton et al., 2016; Sanderson et al., 2016; Wilde et al., 2011), high levels of approval toward psychiatric genetic testing were observed in the present study, with over 90% of respondents expressing approval for the identification of causal genes for mental illness. Notably, for the majority of individuals, two prerequisites to undergo genetic testing were that prediction certainty is high, and that the disorder is preventable, treatable, or severe. These findings are in line with those from a recent study in somatic disorders which showed that tests of undefined clinical and personal utility are associated with a lower degree of patient satisfaction (D'Andrea et al., 2018).

Not surprisingly, the attitude of being against or in favor of identifying genes for mental illnesses was strongly correlated with the attitude of being against or in favor of testing for somatic disorders (τ = 0.80). While these attitudes were correlated with whether the money should rather be invested in other fields of medical research (τ = 0.36 in 2015 and τ = 0.39 in 2003), around half of those who were opposed to the aim of identifying psychiatric genetic risk genes are still in favor of spending money in this area of research. This apparent disparity is most likely due to the urgent need for improved therapies as over 90% of all respondents and 79% of those who were opposed to the aim of identifying psychiatric genetic risk genes approved of the aim of psychiatric genetics for novel treatments. Future research should also investigate in which area(s) patients and relatives would want the available money to be invested in instead.

4.2 | Autonomy to decide whether or not to undergo psychiatric genetic testing and grant access to results of a psychiatric genetic test

The overwhelming majority of participants (94%) favored psychiatric genetic risk testing only in accordance with individuals' own desires and not without their knowledge. This attitude toward the right of autonomous decision-making also extends, albeit to a lesser degree, to children: around 70% held the opinion that children should be able to refuse psychiatric genetic testing even against their parents' wishes (5.10). On the other hand more than 55% stated that children/teenagers should be tested if their parents wished so (5.9). In other words, more than 50% of those agreeing to the child's autonomy are at the same time in favor of overriding it. The relatively low negative correlation of τ = –0.34 between favoring children's autonomous decision-making and genetic testing following parental desires points to the presence of other reasons considered to be more important than the right of the child for its autonomy. Although this question was not asked, it could be assumed that this could be the wish to prevent the onset of a mental illness in children. In any case it is of interest to note that 50% (and 43% in the 2003 study) of those who are in favor of children's autonomy would approve testing them not only for potentially preventable diseases like skin cancer but also for Alzheimer's Disease. The present analysis thus supports previous findings that in general, parents display positive attitudes toward the testing of children for health problems (Lim et al., 2017). Available guidelines recommend that predictive genetic testing should only be performed in minors if there is a potential direct medical benefit, or if preventive measures initiated in childhood will decrease morbidity and mortality (Committee on Bioethics, 2013; EURAT, 2016; European Society of Human Genetics, 2009). However, some experts question this approach, and suggest that it may be too narrow (Hardart & Chung, 2014; Sundby et al., 2018). The findings of some studies suggest that parents may be more reluctant to consent to genetic testing in their children following in-depth discussion of the potential consequences (Bernhardt, Tambor, Fraser, Wissow, & Geller, 2003; Geller, Tambor, Bernhardt, Wissow, & Fraser, 2000). A foretaste of future challenges was provided in a recent large population-based study (Riglin et al., 2017). An association was observed between schizophrenia risk genes and neurodevelopmental impairment in children as young as 4 years old (Riglin et al., 2017). If evaluated on the level of the individual, such knowledge may be beneficial. However, researchers, clinicians, and parents must bear in mind that awareness of such information may also lead to stigmatization and violate the right of the child and future adult not to know (Manzini & Vears, 2018a, 2018b).

Another potential conflict of values—which requires further investigation—likely underlies the following observed disparity of opinions: while almost all respondents stated that data from genetic testing should not be made available to third parties, such as employers or health authorities, about half of them were in favor for obligatory testing of specific groups, for example, individuals with positions of particular responsibility, such as pilots.

4.3 | Data access to results and incidental findings identified in the research context

General interest in the disclosure of results and incidental findings identified in the research context is very high, and over 70% of respondents strongly wished to be informed of both. However, around 40% of respondents would make this decision dependent upon whether the illness in question was treatable, preventable, or severe. Furthermore, around 65% of respondents stated that disclosure of research results should be dependent on the predictive certainty of the respective genetic test. This indicates that while some research participants may have an interest in the research results per se, others may expect benefits directly related to their health or life-planning. This is also reflected by the fact that almost 50% of respondents stated that researchers should actively search for known risk variants for other diseases. Testing for known risk variants during genetic research is the subject of ongoing debate (Lazaro-Munoz et al., 2018). The findings of the present study inform this debate, suggesting that prior to testing, researchers and research participants must achieve a consensus concerning which conditions should be considered severe, and also the degree of preventability and treatability that should be available before disclosure is offered. Irrespective of whether genetic data are to be disclosed, psychiatric genetic researchers must provide potential study participants with information concerning the scientific value and clinical utility of the genetic information, as well as their analytical and clinical validity, particularly

since these often fail to fulfill the standards required in the routine clinical setting (Lazaro-Munoz et al., 2018).

It is of interest to learn that only a minority (~25%) of the participants would agree to leave it to the physician to decide which genetic findings to disclose based on his/her expert knowledge. In general, the majority of respondents valued the right to autonomous decision-making more highly than the duty of care of the study physician. While there is some negative correlation with trust in researchers acting in humanity's best interest ($\tau = -0.19$), the present study cannot answer the question of whether this is grounded in doubts in research physicians' expertise about psychiatric genetics (Appelbaum & Benston, 2017; Marzuillo et al., 2014) or in the desire for autonomous decision-making, or both. Interestingly, for disorders that are treatable or preventable, the majority of respondents considered the duty of the study physician toward the test person more important than the right to autonomous decision-making. This finding supports previous research, which suggests that the duty of care of the study physician is often perceived by research subjects as an implicit aspect of the study physician-study participant relationship (Bunnik, Schermer, & Janssens, 2011; Burke et al., 2014). This points to the problem that, in general, the level of understanding about genetic research among individuals from the general population might be not very high (Chapman et al., 2018; McGill et al., 2018), and, thus, the decision to override the right of the research participant or test person of autonomous decision-making in order to disclose genetic findings (of clinical importance) may prove a difficult and time-consuming undertaking.

Overall, the present findings indicate that attitudes toward the right to autonomous decision-making are contradictory. While the present study was not designed to identify the underlying reasons for this, similar contradictory attitudes were also observed in the 2003 study. Although differences in frequencies between the 2015 and 2003 studies may be statistically significant, we consider these differences of a few percentage points as not relevant as the similarity of response patterns and the similarity of correlations between attitudes in 2015 and 2003 both indicate enduring patterns of contradictory attitudes.

It appears most likely that respondents have different aspects in mind when making conflicting statements. A plausible hypothesis is that individuals adapt their attitude toward, or appraisal of, the right to autonomous decision-making depending on the specific situation, and apply differing moral standards depending on which values are of particular relevance in the respective context. In general, personal autonomy, that is, the individual's right to decide for him/herself, and personal privacy are highly guarded principles. However, research has shown that when a given individual (e.g., a pilot) can represent a possible danger to the wider community, the good of society is valued above the individual's personal autonomy, even if the danger is only potential and the tested individual may never develop the disease (Fulda & Lykens, 2006). A more straightforward explanation for the observed switch in attitude could be that the decision-making process is egoistic in nature, that is, individuals aim to benefit from both their right to autonomous decision-making and maximize their personal safety, simultaneously.

The present study had two main limitations. First, attitudes were assessed in a hypothetical manner, rather than within the real-world context of genetic testing. Second, the cohort was relatively small, and was restricted to patients with affective disorders and independent relatives of patients with affective disorders. However, all of the participants had direct personal experience with major psychiatric illness. Furthermore, for most questionnaire items, the response distributions as well as the correlations were very similar to those obtained in our survey of patients with either affective disorder or schizophrenia and relatives. Due to the large sample size of the 2003 study, many comparisons found significant differences, but these are perhaps not relevant (e.g., differences of 2%).

In conclusion, the present study demonstrated that researchers and future test providers should be aware of the fact that attitudes toward psychiatric genetic testing are complex, and that seemingly levels of high agreement with simple, noncontext-dependent statements may be misleading. Future research is warranted to elucidate why psychiatric genetic research rendered almost a third of respondents uneasy, despite a generally high level of approval for its concepts and goals.

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CONFLICT OF INTEREST

The authors declare that they have no competing interests.

AVAILABILITY OF DATA AND MATERIALS

The data supporting the conclusions of this article is included within the article (and its additional files).

AUTHOR'S CONTRIBUTIONS

JS, SHW, and MR were responsible for all aspects of the study. JS, SHW, MR, LF, MRe, DR, TGS, and FI designed the questionnaire. JS, SHW, MR, JF, JCF, NL, FS, DL, and FD were responsible for the interpretation of the data. JS, SHW, MR, JF, NL, and FD wrote the manuscript. All authors read and approved the final manuscript.

CONSENT FOR PUBLICATION

All study participants and authors have consented to the publication of results.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The respective ethics committees (Bonn and Heidelberg) have approved the study. Written informed consent was obtained from all participants.

ORCID

Jana Strohmaier https://orcid.org/0000-0002-4364-1487
Stephanie H. Witt https://orcid.org/0000-0002-1571-1468

Josef Frank https://orcid.org/0000-0003-4867-9465
Laura Flatau https://orcid.org/0000-0002-3788-9128
Fabian Streit https://orcid.org/0000-0003-1080-4339
Jerome C. Foo https://orcid.org/0000-0003-1067-5725
Markus Reitt https://orcid.org/0000-0001-5685-3887
Dan Rujescu https://orcid.org/0000-0002-1432-313X
Thomas G. Schulze https://orcid.org/0000-0001-6624-2975
Franziska Degenhardt https://orcid.org/0000-0002-1685-8904
Marcella Rietschel https://orcid.org/0000-0002-5236-6149

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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