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The willingness to participate in health research studies of individuals with Turkish migration backgrounds: barriers and resources

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Barriers Research study ABSTRACT

Background.- Lower participation rates of ethnic minorities in health research studies and potential participation barriers are commonly reported.

Methods.- Four semi-structured focus groups of individuals with Turkish migration backgrounds living in Germany were conducted to identify potential participation barriers. Documented statements and superscripted presentation cards by the participants were evaluated with a qualitative content analysis.

Results: The following eight potential reasons for the lower participation rates were identified: role of women, lack of knowledge, lack of interest, German-Turkish interactions, mistrust, anxiety, data privacy protection and benefits of the study. Additionally, the following recruitment strategies to enhance participation rates were found: public relations, especially word-of-mouth promotion and contacting Turkish key figures, (non-) tangible incentives and trust building through transparent communication of the project and its conditions.

Discussion: The findings provide a wide range of potential participation barriers and implications that should be considered to enhance the participation rates of minority populations.

Conclusion: The willingness to participate in health research studies can be increased through particular efforts, which should be tailored to the recruitment of the underrepresented target population.

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1. Introduction

Multiple health research studies, especially in the context of cancer-related research in the US, have reported the lower participation rates of underrepresented populations, such as the elderly, women, residents of rural areas, individuals of low socioeconomic status and ethnic minority groups [10,13,19,20]. In the context of European migration health research, lower participation rates have been found among individuals with migration backgrounds [1,7,16]. Additionally, in a pre-test study of the German National Health Survey for Children and Adolescents, considerable differences in response rates were

identified across different migration groups. The analyses have indicated that individuals with Turkish migration backgrounds participate significantly less than, for example, individuals with Polish migration backgrounds [17,24]. Several barriers have been reported as possible reasons for the reduced participation of underrepresented populations in health research studies, such as fear (e.g. of negative consequences or of being misused as guinea pigs), lack of information, mistrust (e.g., of scientific institutions and their members, of government) and concerns caused by negative experiences with health research studies [4,5,25]. Significant limitations have also been observed in the planning process of research studies, such as the failure to determine adequate goals to successfully recruit ethnic minority groups [2,8,21]. Moreover, research staff may also hold negative views and stigmatisations of ethnic minority groups, and thus, underestimate the willingness and ability of ethnic minority groups to participate in research

* Corresponding Author. E-mail address: d.dingoyan@uke.de (D. Dingoyan) studies [8,6,27]. Commonly suggested methods of building trust through repeated interactions with the target minority population [11,19,25] include involving key persons of the targeted underrepresented community from areas of religion, politics and the healthcare system [2,3,26], utilizing media (e.g., radio and newspaper) and cultural centres [2,9,14], hiring research staff of the targeted population and intercultural education of the field team [2,11,26], providing tangible and non-tangible incentives (e.g., money, bus and taxi tokens, gift certificates for food, movies or videos) [15,26] and disclosing the benefits and risks of study participation [4,11,26]. The present paper provides information about attitudes towards health research studies and potential participation barriers as well as adequate solutions for the successful recruitment of individuals with Turkish migration backgrounds into health research studies.

2. Subjects and methods

2.1. Recruitment and conduction

From March to June 2010, a total of four semi-structured focus groups were conducted with adults with Turkish migration backgrounds who resided in Hamburg. The participants were recruited by the research staff using invitations printed in German and Turkish that were entitled "Your opinion is important to us!" and included a brief explanation of the focus groups. The aim was to include eight individuals per focus group [12] between the ages of 18 and 65 years. As a result of last-minute cancellations and attendance without prior notification, the number of participants varied between 7 and 12 individuals. The majority of the participants were accompanied by friends or relatives. The mean duration of the meetings was 100 minutes, and a compensation of 10 € was offered to each participant. The focus groups were held in Turkish by a female bilingual psychologist who was assisted by a female bilingual student.

Prior to the focus groups, four experts (two with Turkish migration backgrounds and two with broad experiences in field research) were consulted to evaluate key aspects when conducting focus groups with individuals with Turkish migration backgrounds. The experts indicated that this type of investigation could be an unfamiliar situation for the majority of the target group and may lead to uncertainties or inhibitions in open discussion. Furthermore, the experts recommended not video or tape recording the participants for the same reasons. To initiate communication between the participants, they were asked to discuss the first two questions in pairs of two and noted their ideas on coloured presentation cards. Subsequently, the cards were attached to a pin board, and the topics were discussed as a group. Additionally, written notes of the discussion were kept (protocols).

The procedure of the focus groups was semi-structured and included a question guideline. Initially, the participants were asked for their language preferences (German or Turkish) and were informed that their attendance was voluntary. After an introduction of the attendees and a brief presentation of the background and aim of the research study, the participants were asked the following questions:

- Perceived barriers: What do you think are reasons for less willingness of individuals with Turkish migration backgrounds to participate in research studies? With this question, an example was given that referred to enrolment challenges of women with Turkish migration backgrounds in a current survey¹.
- Recommendations: How can individuals with Turkish migration backgrounds be motivated to participate in future research studies?
- Contacting: Can direct personal contact (such as home visits) increase the willingness to participate in research studies?
- Tangible incentive: What amount of money do you consider as appropriate for a three-hour interview?
- Key figures: Can well-known public figures increase the participation of individuals with migration backgrounds in research studies?

Furthermore, two questionnaires were completed. One questionnaire asked for socio-demographic data, and the second questionnaires surveyed the popularity of key figures with Turkish migration backgrounds (on a scale from 0=unpopular to 10= popular). At the end of the meetings, feedback was given by each participant. Because of the different group sizes and the limited time frame, the questions concerning the perceived barriers and the contacting were excluded from two different focus groups.

2.2. Content analysis

The qualitative content analysis of the superscripted presentation cards and documented statements was based on the method of Mayring [18]. The protocols and transcriptions of the presentation cards were translated into German by the bilingual psychologist who moderated the focus groups. In the first stage of the analysis, all statements were paraphrased by one person. In a further stage, two raters independently grouped content coherent statements to inductively form appropriate categories. Typical example sentences and commonly used terms (keywords) were extracted and defined for each category. In the case of inter-rater divergence, the categories were discussed by both raters and coding rules were specified. Subsequently, all categories were revised and compared to the original non-paraphrased statements. Finally, the statements were counted within each category to indicate commonly mentioned topics among all focus groups.

3. Results

3.1. Sample characteristics

A total of 37 individuals with Turkish migration backgrounds and a mean age of 44 years participated in the focus groups. Although it was intended to recruit an equal number of men and women in the focus groups, more women (78%) than men (22%) participated. Twelve participants born in Turkey did not answer the question about their year of migration, without indication of reasons. Further information concerning the sample's characteristics is illustrated in table 1.

¹ personal note from Marion Aichberger (2011)

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