

Why Should We Participate in their Studies? A Focus Group Study of Young Peoples' Attitudes to Health Surveys

Magnusson M^{1*}, Falk LL², Hallmyr M¹ and Chaplin JE³

¹Department of Communication and Public Health, Angered Hospital, Gothenburg, Sweden

²Department of Primary Healthcare, Narhalsan, Vastra Gotaland, Sweden

³Department of Pediatrics, Institute for Clinical Sciences, Sahlgrenska Academy, University of Gothenburg, Sweden

*Corresponding author: Maria Magnusson, PhD, RD, Specialized in Public Health, RN, Angered Hospital, Sjukhuskansliet, Box 63, S-42422 Angered, Sweden, Tel: 46-733-763-157; E-mail: maria.b.magnusson@vgregion.se

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Abstract

Background: The aim of the present study was to explore aspects of health that are relevant to adolescents and young adults and how to frame health related questionnaires so that they are more relevant to them.

Methods: Data were collected by focus-group interviews. Participants were recruited in suburban areas characterized by high unemployment, low income and a high proportion of recent immigrants.

Result: Meaningfulness emerged as important, in parallel with disappointment about not being listened to. Attempts in questionnaires to discover body weight were considered uncomfortable as were questions on ethnicity. Family and friends were considered fundamental for health while money was regarded as less important and with some ambiguity.

Conclusion: Motivation and feedback were aspects that seemed most important in this context. To include the respondent's perspective when constructing questionnaires decreases risk of harm and may increase participation rates. Conducting research without feedback risks decreasing participation in future studies.

Keywords: Adolescents; Empowerment; Health equity; Questionnaires; Surveys

group or person about the ability to perform behaviors or actions that bring desired outcomes [4].

Introduction

Epidemiological research on health related problems faces difficulties concerning recruitment. Additionally, there seem to be untapped opportunities to contribute to narrow the health gap between groups of different socioeconomic status and to promote health in adolescents and young adults that participate.

Health

For this study, we draw our interpretation of health on the constructs sense of coherence and empowerment together with self-efficacy, as defined in Social Cognitive Theory (SCT). Aaron Antonovsky stated that human distress originates from an integration of psychic, social and somatic factors. He described the ability to cope with stressors as being related to a perception of the world as meaningful, comprehensible and manageable. Building on this theory he created the now well-established construct sense of coherence (SOC) [1]. Empowerment enables individuals and groups to take control over their lives, raising issues of participation and strive for social justice [2]. Empowerment has been further described as 'the avenue for people to challenge their internalized powerlessness while also developing real opportunities' [3]. SCT emphasizes the community surrounding any individual as containing important determinants of health. Self-efficacy can be defined as the beliefs in a

Health inequity

Health inequity is a consequence of unequal societies [5]. In the largest Swedish cities, income inequalities become increasingly manifest by the spatial separation of different social groups. Expected life-length in Gothenburg (the second largest city with 540 000 inhabitants) differs between residents in areas with low and high socioeconomic status (SES) respectively by 7.5 years for women and 9.1 years for men [6]. For young people, the prevalence of obesity [7] and localization of poor school results [8] are clear indicators of socioeconomic conditions that are markedly disjoint.

Territorial stigma

Stigma was defined by Goffman as 'The phenomenon whereby an individual with an attribute which is deeply discredited by his/her society is rejected as a result of the attribute. Stigma is a process by which the reaction of others spoils normal identity' [9]. Wacquant coined the expression stigmatized territory for geographical areas where many have low education and income and with high numbers of unemployment and recent migrants, describing them as '... infamous locale that stains the image they have of themselves' [10]. Growing up in a territorially stigmatized area creates a risk that young people internalize the majority's perspective that they are excluded and doomed to fail [8]. This may seriously damage aspects of health that are needed to cope with life in a constructive way, as described above.

To counteract this, societal activities, including research, that aims at improving health in these groups should prioritize to stimulate and encourage SOC, empowerment and self-efficacy.

Selection bias and validity

Low participation from groups with low education, low income and migrant background is a common research problem [11,12]. This is all the more serious since the very same groups are overrepresented when it comes to adverse health outcomes [13]. In studies where the aim is to explore associations between biomedical markers and disease, this selection bias by social and economic status may be of less importance [14]. However, when the aim includes studies of associations between socioeconomically related lifestyle/conditions and outcome, low representation frequently lead to distorted results and conclusions [11]. The deficit in scientifically based knowledge about 'hard to reach' groups [15] has been pointed out as one factor behind sustained or increased inequality [16]. It can also be regarded as unethical from the aspect of social justice that research fails to give voice to people from certain groups.

When epidemiological research involves age comparisons, adolescents, regardless of social strata, tend to be under-represented [17,18]. One explanation can be the 'health journey' which represents a period in life when the acquisition of a sense of autonomy, independence and social skills include experiment with behaviours and lifestyles. During this process, most issues imposed from the grown up world may be defied [19], possibly a ground for not participating in studies.

It seems plausible that validity, too, can be affected by the 'health journey'. Fan et al. examined intentionally inaccurate answers in a study where adolescents used a self-administered questionnaire [20]. They found a group which they named jokesters, meaning adolescents that falsely reported that they were adopted, born in/out of the USA or wore an artificial limb. Jokesters were overrepresented among those reporting negative outcomes for school results and life style habits such as getting drunk, having physical problems, or being involved in fighting. The numbers of jokesters were quite substantial and when their answers were included in the analysis they inflated differences between groups. Reasons behind the behavior, also called mischievous responding are unclear [21].

Questionnaires

Research is, in most societies, regarded as a stable part of society and the content of questionnaires may thus be perceived as normative by the people who are answering them [22]. Therefore, survey questions may cause distress or be offending [23] if they function as exclusionary. If, for example a food frequency questionnaire mainly asks about food that is not included in the respondents diet and is presented as the norm then this could be interpreted as containing an underlying criticism of that person's life-style, this could also affect SOC. The risk of feeling criticized increases the more the implicit culture embedded in the questionnaires differs from the culture of the respondent.

Survey results are sometimes disseminated in a way that increases territorial and other types of stigmatization. For example, Potvin and co-authors, reporting from long-standing research in Canada, reported that 'there was an acute awareness of potential negative outcomes of research in Aboriginal communities, such as community stigmatisation and stereotyping' [24].

To enable epidemiological health related research to increase its contribution to narrowing the health gap, there is a need to develop a better understanding of the perspectives of young people in stigmatized areas. In spite of economic disparities, young people from different social strata have many outlooks in common related to developmental as well as cultural communalities. These communalities will help researchers to develop questionnaires with the potential to be approachable for young people in general.

The aim of this study was to explore what aspects of health are important to include in a health questionnaire from young persons' perspectives, and how questionnaires can be presented in such a way as to improve the participation of adolescents and young adults. Focus is on adolescents in areas where many residents have low education, low income, are unemployed and with recent immigrant background.

Research questions

What seems to be important for the health of young people, from their own perspective?

What are the views of young people on questionnaires regarding layout, content, distribution and feedback?

Methods

Participants

School nurses from two secondary schools and one high school participated in the recruitment process. The schools were in an area where many residents have low education, low income and high unemployment which included many recent immigrants to Sweden. Adolescents from two of the three secondary schools and from the high school consented to participate (Table 1).

School nurses in the secondary schools selected students that they thought would be able to shed light over the subject. All students who were asked consented. The school nurse in the high school suggested to a teacher that participation in the research should be included as a part of the course "life skills" which was approved. There were no boys in this class. The students could choose to opt-out of the research and have physical exercise instead; however a majority of those in the class were willing to participate in the focus group interview. A community youth centre in a similar socio-economic area was identified by snowball technique and contacted in order to recruit an additional group of young men. All participants were given a cinema ticket after the interviews.

Data collection

Focus group interviews were chosen as the data collection method because they are best suited to reveal a shared cultural understanding and to facilitate sharing of influence between researchers/interviewers and interviewees [25]. The focus groups were facilitated by a moderator and an assistant. The moderator opened the sessions by describing low participation in research from youth people in low SES areas as an obstacle for knowledge development; a problem which the participants were invited to help solve. The focus group interview guide was structured according to Kreuger. The approach aimed at facilitating an open discussion concerning participation in health research; the opening question being 'Do you feel that being a student at this school/ youth centre is good for your well-being-if "yes" why, if "no" why not?'

Sessions were audio-recorded and transcribed verbatim. During the sessions the moderator and the assistant both took field notes and after each session the impressions and thoughts of the two researchers was also recorded in order to capture non-verbal information.

Questionnaires

Several questionnaires were used to illustrate and stimulate the discussion, the most extensive questionnaire being one used to examine health in the pre-adult population in the region within which the present study was conducted (Västra Götaland) [26]. This questionnaire was composed of 10 pages of double sided A4 paper, containing questions concerning demographic details, health and illness, life-style choices, sleep, physical activity, height, weight, and well-being. For example one question concerned body shape and was based on nine silhouettes representing body shapes from extremely thin to obese, originally introduced by Stunkard [27] and adapted to a wider age range by Rand [28].

The questionnaire was part of a school based survey involving the physical measurement of over 6000 young people at age 18 years in Gothenburg. Each young person met the researchers and completed the questionnaire in a classroom setting. Two other forms/questionnaires were shown to participants: a template used by school nurses during regular health interviews in high school and a web based self-completion test called 'Find your style' ('Hitta stilen') which also related to health and life style.

Findings

Three focus groups of girls/young women and two focus groups of boys/young men were conducted (Table 1). All participants were informed orally and in writing and signed a consent form. One 14 year old girl participated in the study. Both she and her mother gave written consent. The group sessions were moderated by the first author of this paper. In all interviews there was also an assistant present. In session's I-III and V this role was filled by the third author (a woman) and for group IV the assistant was a man with graduate education on behavioural sciences from the personal network of one of the authors.

The interview guide functioned literally as such and discussions were to a large extent driven by group interaction. In two of the sessions (III and IV) discussions were further stimulated by placing cards with written issues suggested to be valuable for health (money, friends, food, exercise) in different corners of the room and encouraging the participants to place themselves closest to the issue(s) they found relevant.

Focus group	Setting	Number of participants	Gender	Age
I	Gymnasium	5	Girls	17-18
II	Gymnasium	6	Girls	17-18
III	Secondary school	6	Girls	14-16
IV	Secondary school	7	Boys	15-16
V	Community youth centre	4	Boys	Ca20

Table 1: Focus groups: Settings, and data on the groups of participants.

Data analysis

A systematic text condensation as described by Malterud [29,30] was conducted, aiming to develop descriptions rather than new concepts. Focus in the analysis was on manifest content. After a first naïve reading of the transcripts and field notes a general impression of the data was established. Helped by re-reading and listening to the audiotapes three of the authors coded two of the interviews, guided by the research questions [31].

When consensus was reached the first author coded the rest of the data, going back in the material and re-coding when needed and then constructed subgroups within the codes. From then the subgroups were the analytical unit. Each subgroup was described and headings for the subgroups were developed. Codes and subgroups were then compared to the whole from which they were derived in order to avoid fragmentation, and a systematic search for data that contradicted the headings was conducted. After this step, the result was discussed in the research group and minor adjustments were made (Table 2). The result is presented below by codes and subgroups.

Code	Subgroups
Determinants of health	Lifestyle issues
	Money for good and evil
Belongingness	Friends and family
	Ethnicity
Body size and looks are charged subjects	Looks are important for self esteem
	To be overweight is to be stigmatized
Disappointments	Grown-up world
	Who benefits from research?
Aspects of questionnaires	Potentially harmful questions
	Comfortable questions
	Practical aspects

Table 2: Codes and subgroups.

Determinants of Health

Lifestyle issues

There was an agreement that food and exercise are important for health, in addition enough mental strength to overcome social or physical adversities; having high status employment and an environment without pollution were also mentioned. Some participants stated that they had problems concerning overconsumption and dependency on sugar, smoking and that they took too little exercise.

'And if you have a job that is considered nice by society you will feel much better' (Group V).

Money for good and evil

The participants perceived not having money as a potential obstacle to achieve a healthy life-style, and as a potential factor leading to an unhealthy life-style. Participants pointed out that you need a certain

amount of money to achieve an acceptable living standard and that a life-style that includes eating the best food available and joining a gym requires more than the minimum income allows.

The negative aspects of having money were also highlighted for example if peers buy fashion clothes and go on vacation trips it can arouse envy and that money can't buy things that really matters, like love and friends. A fifteen year old boy claimed that lack of money could be beneficial because if you don't have money you can't buy drugs. One participant disagreed that money was related to health. She claimed that: '... money will not come if you do not feel well and too much money will not be helpful.' (Group III).

Belongingness

Friends and family

Friends and family were highlighted as the most important factors for wellbeing.

In all the focus groups this was confirmed, giving the feeling that it was fundamental and at the same time an intimate matter, connected to feelings that one did not want to discuss. When school was described in positive terms, it was mostly from the context of friends.

Ethnicity

One of the aspects of the example questionnaire was that it tried to elicit information concerning height in order to establish a new Swedish standard for growth. Therefore, it was important to identify the heights of the respondents and their parents. This involved questions concerning ethnicity as genetic disposition to height is a major factor in final height and growth. The lead-in to a question about parental ethnicity was; 'Tallness varies across the world and therefore we want to know where your parents were born'. Some focus group participants were concerned about this question. One participant said

'Why do they ask where you yourself and your parents were born – is it because some of us look like foreigners?' (Group II).

Several participants expressed worries concerning the questions on ethnicity, however the young men in group V stated that it was not problematic. One girl made associations with racism and there were discussions about people with certain looks not being regarded as Swedish.

Body size and looks are charged subjects

Looks are important for self-esteem: Several aspects of the association between looks and well-being were expressed. In the male focus groups, being fit and having a muscular body was emphasized as an indication of health. Some girls said that it was of great importance for them to 'fix themselves' before meeting with other people. One girl said that she might state in the questionnaire that her body size was smaller than it really was because it would make her feel better.

To be overweight is to be stigmatized

Strong negative feelings were expressed in relation to questions that used a body silhouette to indicate body shape. Being fat and knowing that everybody in the classroom knows which square you have to fill in was highlighted as most painful. Several participants had the opinion that such questions should not be included. In the sessions for the

college girls much focus was on comparing the body silhouettes and commenting upon oneself and each other.

Disappointments

Grown-up world

Having to answer questions concerning healthcare seemed pointless to some students because they believed that it would not result in any change. Discussions emerged describing budget problems at school level as overwhelming, affecting many aspects important for the students, such as teaching (including marking), food, school environment and pedagogic features like common school trips for educational purposes. Some students claimed that they had never met the school nurse or talked about health in college.

Who benefits from research?

A feeling of not being listened to, in spite of having filled in many questionnaires during the years, was prominent in the data. This feeling was referred to as an explanation as to why some people did not answer questionnaires, or, as it was claimed, did not answer appropriately.

Why research is done and what it means to be a participant was questioned and discussed from different perspectives. 'But you have to feel that you are listened to and understand (otherwise) why should you answer' (Group V). In group IV it was suggested that the only people who gained from research were the researchers themselves who got paid for doing it.

Aspects of Questionnaire Construction

Potentially harmful questions

Objections were raised against questions about parental origin. Questions about the situation at home may be awkward to answer, for example if people do not know their biological parents. Participants said that people who are not content with themselves or with their lifestyle in general, may experience negative emotions from answering certain questions and they might invent answers in order to support a more positive self-image. One girl recalled questionnaires where multiple questions referred to the same thing and said that it made her feel bad. The questions about the body size of friends seemed to be bewildering and to some extent problematic. Boys in group IV presupposed that 'beefy' persons were more dominant, speculated that researchers wanted to examine social patterns. In one of the female groups it was suggested that researchers wanted to know if the respondent envied their friend, if she had a 'good-looking butt'.

Comfortable questions

Questions about food were generally considered to be easy to answer, however it was remarked that it may be difficult to remember what you have eaten. Adequate examples of food types were represented so that the question could be answered. Questions concerning the mood state of the participants were also considered to be comfortable to answer. Some thought that people who are unhappy with their weight or food habits, may like to fill in a questionnaire because they believe that they will get some help. One view, expressed in group V, was that in anonymous surveys any questions on health can be put. In this group it was also stated that questions about

ethnicity and tallness were also acceptable if the questionnaire was anonymous.

Practical aspects

The idea of sending a questionnaire home to the participant was rejected.

Facebook and Internet were considered to be bad alternatives for surveys because claims of secrecy could not be trusted to function when information is transmitted via the internet. The magnitude of the most extensive questionnaire (17 pages of questions) was criticized. One participant expressed that she felt discomfort when a questionnaire contained several questions that aimed at getting the same information. Visual analogue scales were approved of but it was highlighted by some respondents that people sometimes put crosses anywhere just to complete the questionnaire, especially if you are in class and allowed to do something more tempting afterwards (like taking a break). Interviews were mentioned as easier and better ways to get accurate information, while the possibility to make written comments was rejected as unlikely to ever work. In group V it was suggested to anchor surveys to local campaigns, for example it would be possible to use a campaign logo that was positive and well known locally.

Discussion

In the present study meaningfulness emerged as important, in parallel with disappointment about not being listened to in the past. Attempts in questionnaires to discover body weight, including perceptions of body image, were considered uncomfortable and potentially painful, as were questions on ethnicity. Family and friends seemed to be fundamental for health while money was regarded as less important and with some ambiguousness.

One purpose behind this study was to contribute to decrease health inequity. Young people from areas of low SES were interviewed on how questionnaires should be constructed in order to address themes relevant to their health, formulate these in a way that promotes health, and that would make them willing to participate in a health survey. Insensitive questionnaire design may lead to greater exclusion of this age group and greater exclusion of young people in areas of low SES than elsewhere. The results should not be regarded as exclusive to any social strata but can be used when developing health questionnaires for adolescents in general.

Sensitive areas to investigate

Body weight is generally a big issue in the health discourse of young people. It is reported to often be connected to negative feelings and, especially overweight and obesity, to stigmatization [32]. This is confirmed in our data. Some participating girls were troubled by the fact that peers who were 'too big' or 'too small' would be reminded, through the questionnaire, that body weight is an important aspect of health. Additionally using a norm based question could lead to supporting exclusion behaviour. For many overweight adolescents bullying - commonly inspired by body appearance - is a constant threat [33]. Norm based questions could be seen as legitimizing bullying behaviour.

A question on ethnicity of parents stimulated discussion about who 'looks like a Swede' which, however vague, was being associated with racism. Such questions are not asked within in a neutral 'scientific'

zone but in a society with documented structural discrimination related to, among other issues, ethnicity [34]. Considering the rise of racist and immigrant-hostile movements in recent years where ethnic origins are placed on a norm scale, identifying oneself as outside "normal identity" [9] can be linked to fear of, and/or experienced, stigmatization. The International Committee of Medical Journal Editors' has made the statement that 'Authors should define how they measured race or ethnicity and justify their relevance'. It seems important that this is taken into considerations for future research.

Group V differed from the others by expressing what might be described as a greater understanding of the researcher's point of view - in other words it is ok to answer most question as long as it is anonymous. The members of this group were older and the setting - youth club instead of school - was also different, and potentially open to other perspectives.

Distrust

Respondents' distrust of researchers and other distributors of questionnaires and surveys seemingly emerged from the experienced lack of feedback and absence of any noticeable effect of the research. The belief that you will get help if your questionnaire answers reveal problems (which was presented as a motivation for completing a questionnaire) is unlikely to be supported within epidemiological research and illustrates a misunderstanding of how research is carried out on a population basis. Such beliefs therefore likely lead to confusion and disappointment. One participant expressed that she felt discomfort when a questionnaire contained several questions that aimed at getting the same information. Negative reactions to the apparent repetition of the same question is in line with findings by Nilsson et al. who in a study among Swedish adults found that such repetitive questions, commonly used for validating, were perceived as manipulative or controlling and could foster feelings of being regarded as an object rather than a respected individual [23].

Wallerstein described distrust, disappointment and confusion as contributing to a subjective feeling of powerlessness and as a broad risk factor for adverse health outcomes [3]. For some people this may pose a threat to the feeling that the world makes sense, potentially damaging SOC [1].

Motivation

Wenemark verified the hypothesis that type of motivation (intrinsic vs. extrinsic) affected response rate in a population-based self-administered health survey aimed at ages 18-84 [35]. Filling in a questionnaire that made participants feel respected and which allowed them to contribute to knowledge increased the response rate, improved the quality of the data and increased the participant's satisfaction with the research such that the likelihood of future participation was more likely to occur. Ampt et al. reported improvement in participation rates after including children in design of a survey [36]. The concept behind participatory research (PR) is useful in this context. The foundation includes sharing of power, not least over the dissemination of research results, between researcher and participants [37]. Another vital aspect is the acknowledgment that lay knowledge and scientifically gained knowledge play equally important roles in the research process. One potential effect of PR is increased participation on the basis of participants' trust for the researchers and perceived relevance of the research [38]. Considering the characteristics of the health journey in this age group, with its inherent strive to defy any imposed issue [19],

considering aspects of participation should be even more important when developing questionnaires with young people.

The more completed forms, the more scientific knowledge?

Our results imply that shared power might lead to the exclusion of questions on issues that are of great relevance for health, such as body weight, discrimination, family income and employment. Another disadvantage compared to traditional researcher's perspective is that surveys that build on local conditions and/or vary by study group are complicated to compare. On the other hand, low and biased participation also pose a threat to scientific knowledge. It is common that surveys among children and adolescents are conducted in school environment and this may constitute, not only a pressure to fill in the form, but may also yield threats towards validity and reliability [20,39]. In our interviews there were hints that reliability of school based surveys was doubtful. On the other hand, to send questionnaires home or to use a web-based approach were rejected by some participants.

Ethical aspects

Participants suggested that surveys should be co-designed by members of the communities or groups that were targeted to answer them, implying that researchers should explain thoroughly why they should participate and how the results can contribute to changing their lives. This touches on aspects of health such as SOC, empowerment and self-efficacy and thus aligns with ethical demands that research shall not harm. Taking into consideration segregation, territorial stigma and the WHO which strives for health equity [40] it is even more important to assure that issues of empowerment are integrated into research with young people from the lower strata of the social ladder. By ignoring the importance of the respondent's views in the development of our research instruments we will most probably decrease participation rates, especially from the most vulnerable groups and potentially damage our ability to understand the true nature of the health equality divide.

Strengths and limitations

Recruitment, data collection and analysis were transparent and in accordance with established methods. The content and variation of data allowed for exploration of the research questions.

More interviews with adolescents from different social strata could have offered detailed insights in similarities and disparities between them.

Conclusion

Motivation and feedback were the aspects that seemed most important to consider when planning for surveys among adolescents.

Questions on body weight, body size and ethnicity were considered uncomfortable to answer which should be taken into consideration by researchers.

Implications

To include respondent's perspective when constructing questionnaires decreases risk of harm and may increase participation rates. Research without feedback to participants risks decreasing future participation.

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Short Biographies

Dr Maria Magnusson is Registered Dietician and Registered Nurse. She has a position as Public Health Planner at Angered Hospital, Gothenburg, Västra Götaland Region. Marias' research build on participatory interventions and aim at develop knowledge that contribute to increased health equity. She defended her doctoral thesis; "Childhood obesity prevention in the context of socioeconomic status and migration" in 2011.

Lena Ljungkrona Falk is a Registered Dietitian at the Child Health Care Centers (CHCC) in the Region of Västra Götaland. Her work focuses on health promotion to the families and children in the Swedish CHCC and support for the Health Care nurses in this areas.

Moa Hallmyr holds a Bachelor in Public Health. Throughout her studies she has focused on the process of migration and its effects on health, with a special interest in health equity. In her Bachelor thesis she explored Community based participatory research.

Dr John Chaplin is an Associate Professor in experimental paediatrics. He is a chartered psychologist in Sweden and the United Kingdom and an Associate Fellow of the British Psychological Society. He works at the Institute for Clinical Sciences, Sahlgrenska Academy at Gothenburg University. His research concerns the measurement of quality-of-life related to chronic illness and its treatment. His focus is on how to incorporate the patient's perspective into healthcare management.

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