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The respondent's perspective in health-related surveys

The role of motivation

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To Robert, Gustav and Alva

Let us not become a profession that focuses mainly on technical survey issues, [instead of] the people and issues that we are studying.

Schulman 2003 p. 458

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ABSTRACT

Declining response rates are threatening the usefulness of and confidence in survey data. Survey practitioners have therefore studied why nonrespondents refuse to respond and have tried to counter the declining response rates by intensified follow-up methods. Such efforts sometimes yield negative reactions among respondents. This thesis focuses on the respondent's perspective in self-administered health-related surveys. The aim was to investigate positive and negative aspects that respondents experience when participating in surveys, to study factors that could increase motivation and to study possibilities to increase response rates in a way that promotes data quality as well as positive experiences among respondents. Self-Determination Theory is a motivation theory that was used as a theoretical framework.

Paper I is a study regarding two self-administered health questionnaires among patients in 20 intervention groups in 18 Swedish hospitals. Paper II is a qualitative analysis of data from telephone interviews with respondents to a self-administered health-related survey of the population in the county of Östergötland. Paper III is a randomized experiment in a self-administered survey of a random sample of parents in the municipality of Stockholm. Paper IV is an experimental study concerning a self-administered health questionnaire in a random sample of the general adult population in the county of Östergötland.

The results from paper I show that questionnaire length and ease of response were not crucial arguments in choosing between two health questionnaires for use in routine health care. Instead, the most common motives for the choice concerned aspects of the questions' comprehensiveness and ability to describe the health condition. Respondent satisfaction as described by respondents in paper II includes being able to give correct and truthful information as well as reflection and new insights from the questions. Respondent burden includes experiences of being manipulated or controlled by the researcher as well as worry, anxiety or sadness caused by the questions. Experiences of satisfaction and burden differed depending on the respondents' primary motive for participating in surveys. The findings of paper III illustrate that the use of lottery tickets as incentives to parents may be less valuable or even harmful as a means of increasing response rates. In paper IV a survey design inspired by Self-Determination Theory yielded higher satisfaction among respondents and improved response rates with similar or better data quality compared with a standard design.

Focusing on the respondents' perspective provided important new knowledge. The results show a broad spectrum of positive as well as negative aspects of survey participation. The results support Self-Determination Theory as a useful theoretical framework for studying motivation in survey research and an interesting additional source to provide ideas on how to design surveys with the potential to motivate respondents. The results suggest that it is possible to improve response rates in a way that promotes data quality as well as positive experiences among the respondents.

PREFACE

I started to work with my first questionnaire survey in 1989 and since then I have worked with many different surveys in different fields. For a long time I tried to avoid work assignments that involved questionnaire studies. Response rates were lower with every survey and doubts about the resulting data quality restricted the impact and usability of the results. Yet questionnaire studies have haunted me in all my different employments. In 2002 I started to work at the Centre for Public Health Sciences and because I had a lot of experience of surveys, my first assignment was a self-administered survey on mental health that was to be sent to 13 000 inhabitants. A recent similar survey had a response rate below 50% and some people had reacted with annoyance over reminders. We decided to try some other ideas in which the highest priority would be to make sure that people who decided to participate should feel that they could "tell their story" and give truthful and relevant information. Choosing not to participate should be respected and therefore only one non-persuasive reminder was used to minimize risks of worsening any mental health problems. Respondent-oriented factors were given higher priority in the study design than obtaining the highest possible response rate. This survey changed my world. We obtained a response rate of 66% but even more important; we experienced a unique commitment among respondents.

Maybe the respondents appreciated open-ended questions as genuine interest by us in listening to what they had to say, maybe they felt secure by the use of anonymity, or maybe they had better control of the process by our non-offensive follow-up strategy. Suddenly there were so many things to try in experiments and many thoughts about what the respondents had actually experienced and how their experiences can be studied. The idea to this thesis was born.

LIST OF PAPERS

This thesis is based on the following studies:

I. Respondent satisfaction regarding SF-36 and EQ-5D, and patients' perspectives concerning health outcome assessment within routine health care.
Nilsson Evalill, Wenemark Marika, Bendtsen Preben, Kristenson Margareta
Quality of Life Research 2007; 16(10): 1647–1654.

II. Respondent satisfaction and respondent burden among differently motivated participants in a health-related survey.
Wenemark Marika, Hollman Frisman Gunilla, Svensson Tommy, Kristenson Margareta
Field Methods 2010; 22(4): (in press).

III. Can incentives undermine intrinsic motivation to participate in epidemiologic surveys?
Wenemark Marika, Vernby Åsa, Lindahl Norberg Annika
European Journal of Epidemiology 2010; 25(4): 231–235.

IV. Applying motivation theory to achieve increased respondent satisfaction, response rate and data quality in a self-administered survey.
Wenemark Marika, Persson Andreas, Noorlind Brage Helle, Svensson Tommy, Kristenson Margareta
Submitted

ABBREVIATIONS

EQ-5D	EuroQol 5-Dimensions
HPH	Health Promoting Hospitals
HRQoL	Health-Related Quality of Life
LSH study	Life conditions, Stress and Health study
SDT	Self-Determination Theory
SF-36	Short Form-36
VAS	Visual Analogue Scale
IM	Intrinsic Motivation
IMI	Intrinsic Motivation Inventory
TDM	Tailored Design Method

INTRODUCTION

Surveys are an important source of information in modern society. They provide a valuable way to obtain information from individual citizens, employees, households, patients, consumers and establishments. The information is widely used for example by governments and researchers. Surveys can also be seen as an important means of giving citizens a voice in a democratic society.

Response rates to surveys are, however, declining in many countries. The response rate is often perceived as an important indicator of the quality of a survey and low response rates may have severe consequences in terms of biased information. Declining response rates are therefore threatening the usefulness and trustworthiness of survey data.

Survey practitioners have tried to counter declining response rates by intensifying follow-up methods, using persuasion techniques, multiple reminders and applying refusal conversion techniques. These efforts have sometimes been shown to yield negative reactions among respondents, possibly leading to reduced willingness to participate in similar studies in the future. Thus, even if such methods have been successful in improving response rates in specific surveys, they do not seem to offer a long-term solution to the problem of declining response rates. Indeed, they may even worsen the problem.

The rationale of why nonrespondents refuse to participate in surveys has been the subject of many studies. However, there is a paucity of research on respondents' motives for participation. Few studies have investigated factors that may facilitate respondents' motivation, not only to participate but also to be committed and answer questions carefully and thoughtfully. This thesis focuses on the respondent's perspective in self-administered health-related surveys.

EMPIRICAL AND THEORETICAL FRAMEWORK

Declining response rates

Many factors are important to achieve reliable survey data. It is, for example, important to be able to draw a representative sample from the population investigated. However, a crucial aspect of survey quality is that information can be gathered from the individuals in the sample. Respondents who cannot be contacted and respondents who are unable to or refuse to participate lead to nonresponse, which may have severe effects on survey quality in terms of biased information (Groves et al. 2002, Van Loon et al. 2003, Tolonen et al. 2005, Gundgaard et al. 2008). Nonresponse also increases survey costs because of the increased cost of efforts for nonresponse reduction and for nonresponse adjustment (statistically accounting for nonresponse for example by using auxiliary information). The response rate is often perceived as an indicator of the quality of the survey. A high response rate is therefore important for the image of survey organizations and low response rates may affect the trustworthiness and usefulness of survey data. Declining response rates is therefore a challenging problem for survey researchers, survey practitioners and users of survey data.

Several authors have shown that response rates to surveys are declining in many countries (de Leeuw and de Heer 2002, Curtin et al. 2005). Tolonen et al. (2006) report declining response rates in a longitudinal study over 25 years in Finland; response rates for men aged 15–24 years declined from 86% in 1978 to 52% in 2002. From 1999, three reminders were used instead of the original two. In a Danish public health survey, the response rates declined for a face-to-face interview from 80% in 1987 to 67% in 2005, and for a self-administered questionnaire from 68% in 1994 to 51% in 2005 (Ekholm et al. 2009). These declines were particularly marked among the young.

Statistics Sweden used to present response rates in recurrent surveys in the report *Bortfallsbarometern*. The last report showed increased nonresponse in The Survey on Living Conditions (ULF-undersökningen) from 14% in 1980 to 24% in 2000 and The Household Budget Survey (Utgiftsbarometern) reached the highest nonresponse level ever, at 50% in 2001 (Kristiansson et al. 2003). They conclude that nonresponse is worrying because it keeps increasing despite more efforts to reduce nonresponse. Statistics Sweden has also reported an increase of nonresponse in the Labour Force Survey (AKU-undersökningen) from a few percentages in 1970 to 12–13% in 1995 (Japec et al. 1997).

The Riks-SOM survey is a Swedish survey focusing on society, opinion and media and has been performed each autumn since 1986. This survey has experienced declining response rates, especially among young people and men (figure 1) (Nilsson 2009). The overall response rate has declined from 67% in 1987 to 55% in 2009. Among people aged 20–24 years, the response rate has decreased from 64% in 1995 to 43% in 2009.

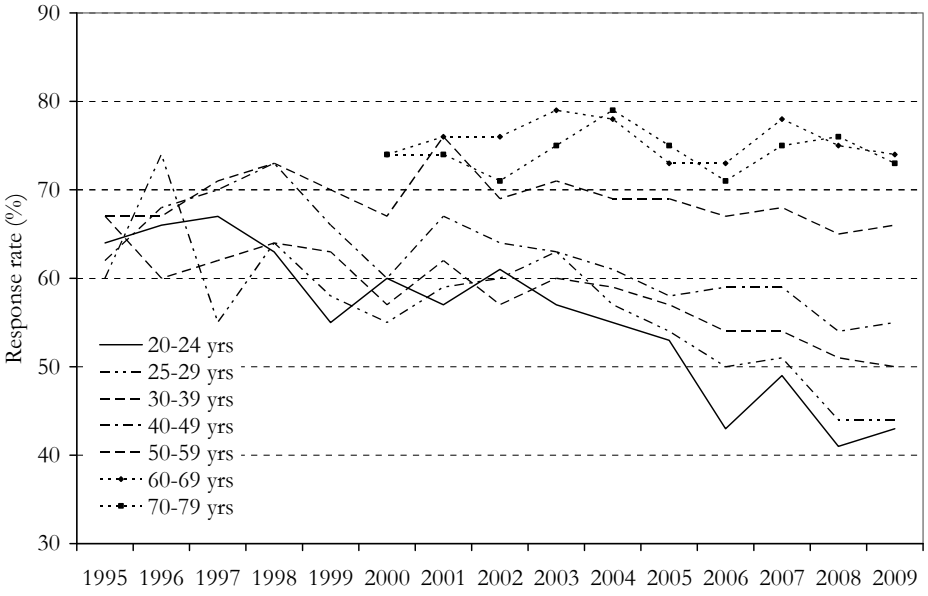


Figure 1. Response rates in Riks-SOM 1995–2009 (data from SOM-institutet).

In this study, follow-up strategies have been intensified over the years by using several telephone reminders and recently also by reminder calls to cellular phones. In 2009, the data collection procedure included up to nine contacts during the five month data collection period: a pre-notification postcard, the original questionnaire, a thank you reminder postcard, a postal reminder with a new questionnaire enclosed, three telephone reminders, a postal reminder with a new questionnaire enclosed and finally a nonresponse card asking for reasons for non-participation with a new questionnaire enclosed.

It is difficult to establish the real magnitude of the decline because efforts to increase response have often been enhanced over time. However, it seems that most data show declining response rates in Scandinavia just as in other European countries and the United States. It is also clear that response rates are declining despite intensified follow-up strategies.

Several researchers and authors have provided possible explanations for the declining response rates (Tourangeau 2004, Galea and Tracy 2007, Dillman et al. 2009). Increased use of telemarketing has led to new techniques to persuade people to buy something which might abuse the public's trust and undermine the credibility of surveys e.g. selling under the guise of a survey (sugging) (Galea and Tracy 2007, Dillman et al. 2009). Answering machines and caller ID give people opportunities to screen their calls. It has become not only socially accepted but perhaps even necessary for people to reject proposals and invitations. In Sweden the percentage of households that have blocked their landline telephone number for telemarketing has increased rapidly and reached 48% in 2009 (data from Föreningen NIX-Telefon and The Swedish Post and Telecom Agency). This could be an indication that people do not want to be disturbed or a reaction against more aggressive telemarketing methods, which could also affect the possibilities to perform surveys.

Statistics Sweden has reported reduced willingness to cooperate among respondents and suggests that debates about statistics in the media could influence the survey climate (Kristiansson et al. 2003). Galea and Tracy (2007) further suggest that there is a growing disillusionment with science that may have arisen from contradictory messages from research on recommendations for nutrition, health screening and so on. Several authors

have addressed the role of the survey climate to explain unit nonresponse (Groves and Couper 1998). Some have suggested that there is an overall decline in civic engagement, such as participation in community organizations, elections and other activities (Galea and Tracy 2007). People increasingly choose to participate only when the issue is particularly salient with their lives. There is also a demographic shift with an increasing number of elderly who are unable to participate because of physical infirmities as well as a large number of immigrants who are unable to participate because of language problems (Tourangeau 2004). Some authors claim that there have been an increasing number of requests to participate in epidemiologic studies and that the studies have become more demanding of participants e.g. including biologic sampling (Galea and Tracy 2007). Development of computers and statistical analysis programs has led to an increasing interest in technical aspects of questions which could lead to more abstract and artificial questions.

Theories of survey participation

Participation theories is one way for researchers to understand why people choose to participate or not in surveys. This chapter briefly summarizes some of the proposed theories for survey participation.

One line of research has applied psychological mechanisms to the survey setting. Cialdini (1984) proposed six psychological factors that can influence compliance with a request to perform a task: reciprocity, social validation, authority, scarcity, liking and consistency. Reciprocity is often mentioned as the factor explaining why prepaid incentives are successful to increase response rates (Groves et al. 1992). The principles of social validation and scarcity is used in cover letters by establishing a norm that most people participate in the survey (*many have already answered...*) and by presenting the opportunity to participate as limited (*you have been selected among many people to represent...*) (Groves et al. 1992, Biemer and Lyberg 2003). According to the principles of authority and liking, participation should be stimulated when a survey organization is perceived as an authority and when the request comes from someone with similar attitudes and background (Groves et al. 1992). If someone has agreed to a small

initial request, they are more willing to comply with further requests consistent with the first commitment, which is used in foot-in-the-door strategies (Groves and Couper 1998). These principles have been investigated in many studies and have inspired several theories of survey participation (Luppes 1995). However, the effects of the principles of authority and social validation have also been questioned (Dijkstra and Smit 2002).

Groves and Couper (1998) built a conceptual framework for survey participation. In this framework, in addition to the influence of the interviewer and the respondent–interviewer interaction in interview surveys, participation is influenced by:

- societal level factors (economic conditions, survey-taking climate, neighbourhood characteristics)
- attributes of survey design (mode of administration, respondent selection, incentives, length and topic of survey)
- characteristics of the sample person (age, gender, household structure, past experiences of surveys)

Groves et al. (2000) have developed a theory of survey participation which they called *the leverage-salience theory*. The leverage-salience theory suggests that different individuals place different importance on different features of the survey request. A person with limited free time might be sensitive to the length of the survey, but a person interested in the topic might accept a very long survey. The influence of each survey design feature depends on both the value the person places on a specific feature (leverage) and how much emphasis is put on that feature by the researcher (salience).

Another approach to explain survey participation is Dillman's *Tailored Design Method* (TDM) which is based on social exchange theory (Dillman et al. 2009). The theory of social exchange suggests that actions of individuals are motivated by the return these actions are expected to bring. There are three crucial factors to increase survey participation: perceived rewards should be increased, perceived costs should be reduced and trust should be established. The TDM method has many similarities with the leverage-salience theory and also emphasizes some of Cialdini's principles (social validation, scarcity, authority and consistency). Other suggested ways of

increasing the benefits of participation according to TDM are to appeal to people's helping tendencies, to show positive regard, to say thank you and to give tangible rewards. Ways of decreasing the costs include making it convenient to respond, avoiding subordinating language, making the questionnaire short and easy to complete and minimizing requests for sensitive information. Dillman suggests that trust in social exchange theory is the expectation that rewards will outweigh the costs. For example, by providing a token of appreciation in advance, the researcher shows trust in respondents. Making the task appear important will increase the trust that something useful will happen as a result of the study. Trust may also be established by a request that comes from an authoritative source and by explaining the efforts that will be taken to ensure the confidentiality and security of people's responses.

It has also been proposed that participation can be described by a cost–benefit calculation. Participants will be more likely to take part when they perceive that the benefits outweigh the costs and that it is the cost–benefit ratio that predicts participation (Dunn and Gordon 2005, Singer and Couper 2008). Closely related to cost in those theories is the concept of respondent burden. Respondent burden relates to negative aspects of survey participation and has been defined in several ways. The most common definitions include cognitive burden and time burden. Biemer and Lyberg (2003) include four aspects: questionnaire length, workload in terms of time and effort, pressure the respondent might feel when being confronted with questions and the number of survey requests the respondent receives within a certain period.

These theories provide frameworks for studying the respondent's decision to participate or not in a survey. In a telephone survey, this decision is made within the first few seconds of interaction between interviewer and respondent. The interviewer often gets at least some information on the reasons for denial. In a self-administered questionnaire there is generally no information about whether nonrespondents received the questionnaire, chose not to participate, started to fill in the questionnaire but for some reason did not finish it or if they finished it but did not sent it back. All these different actions appear as nonresponse to the researcher. A respondent who decides to participate in a survey but for some reason does not complete it will result in a breakoff. Proposed models for survey

breakoff are therefore also relevant for learning more about nonresponse in self-administered surveys. In web-based surveys, it is possible to study exactly where in the questionnaire breakoffs occur and thereby gain more knowledge. A suggested framework for understanding web survey participation includes a decision to start the survey, multiple subsequent decisions to continue answering as well as decisions to answer each question (Peytchev et al. 2009). Peytchev et al. (2009) also include page and question characteristics such as question content and question type as factors that influence the decision to continue answering and to answer specific questions or not.

In summary, several theories for survey participation have been proposed. They rely on psychological mechanisms and theories of social exchange and have contributed to the development of survey practice.

Efforts to increase response rates

Researchers have tried two different ways of dealing with declining response rates. The first involves strategies to reduce nonresponse and the second involves statistically adjusting for nonresponse (post-survey adjustments) by the use of register data for example. This thesis mainly concerns the first approach.

Steadily decreasing response rates have forced survey methodologists to strengthen their efforts to increase participation (Edwards et al. 2008). Some of the efforts are also of benefit to the respondents. One example of this is the increasing use of mixed-modes. Mail surveys, telephone surveys and face-to-face interviews, which used to be three separate ways to perform surveys, are often used today in combination to achieve reasonable response rates. This means that respondents sometimes initially can choose a mode that suits them and sometimes are offered an alternative mode that suits them better after not responding to the initial mode. Another development that is of benefit to researchers as well as respondents is the focus on the cognitive aspects of questions (Sudman et al. 1996). Cognitive interviewing is a tool to identify problems with the cognitive process of answering a question (i.e. to understand the question, retrieve information,

make judgements or estimations and report a response to the question) (Willis 2005). Cognitive interviewing is now standard practice in questionnaire design.

Declining response rates have also led to practices that are not as beneficial to respondents. Persuasion and manipulation are widely used in survey practice. Persuasion is done by the practice of refusal aversion (to avoid a refusal in the first place) as well as refusal conversion (to convert a refusal) (O'Brien et al. 2006). Tailoring and foot-in-the-door strategies involve learning more about the respondent in order to maintain interaction, tailor persuasion techniques and thereby make it more difficult for respondents to deny participation (Groves and McGonagle 2001, Biemer and Lyberg 2003).

"Prolonged interaction" means maintaining a conversation long enough to identifying cues that allow the interviewer to tailor the approach by listening to the reasons the respondent is giving for not wanting to participate and responding appropriately by using effective persuaders to counter argue those reasons (Biemer and Lyberg 2003). Sometimes interviewers record personal details of contacts with panel respondents and pass this information to interviewers in upcoming rounds to achieve the highest possible panel maintenance. These observations include whether or not the respondent was cooperative and whether they had any health or language problems (Laurie et al. 1999). Tourangeau and Ye (2009 p. 342) showed that more respondents agreed to complete a second interview when stating "Unfortunately, the information you've already provided to us will be much less valuable unless you complete the second interview" compared with "The information you've already provided to us will be a lot more valuable if you complete the second interview". The respondents presumably do not want the information they have already provided to be less valuable and therefore they agree to continue.

The most common way of increasing response rates is probably by intensified follow-up methods such as multiple reminders. The number of contact attempts is increasing in many self-administered and interview surveys. Keeter et al. (2006) defined "hardest-to-reach" respondents as those who refused the interview at least twice before complying and/or required 21 or more calls to complete the interview.

Green (1996 p. 449) suggests that a warning about reminders can improve response rates and reduce the cost of sending reminders "Because a good response rate is so important, we will be sending reminders to nonrespondents. To avoid this irritant, why not fill it in now and get it over with?!" Another common strategy is prepaid incentives, which differ from promised incentives because they may create a sense of obligation (Tourangeau 2004).

These methods have in common that they aim at making it difficult for the respondent to deny participation. These practices also raise the question whether survey methodologists, in striving for increased participation, stretch the boundaries of ethically acceptable practices.

Ethical problems in efforts to increase response rates

Respect for autonomy is one of the most important moral principles (Beauchamp and Childress 2001). The voluntariness of participation in research can be violated by coercion, persuasion and manipulation. Informed consent is therefore an essential issue when recruiting participants in research. In the case of a self-administered survey, a respondent is not required to specifically express willingness to participate in the survey. Informed consent is generally accepted to be present when a respondent returns the completed questionnaire. Refusal is generally accepted if a respondent returns a blank questionnaire or declines participation by telephone, mail or e-mail. An unreturned questionnaire is usually not accepted as an expression of refusal. It is therefore common practice to send reminders to the respondent as long as the accompanying letters express the voluntariness of participating in the survey. Persuasion is widely used in interview surveys among individuals who have already refused participation. The question is if respondents disapprove of these methods and feel manipulated or persuaded. How many reminders can for example be sent to respondents without violating voluntariness?

Singer and Bossarte (2006) have adressed the question if incentives are coercive and Singer and Couper (2008) have argued that incentives are not coercive because respondents do not accept higher risks when offered larger incentives. Few studies, however, follow up on respondents'

perceived experiences of strategies to increase response rates. Prepaid incentives have been shown to sometimes cause irritation among respondents and some respondents even return the incentive (Singer 2002). Taking the extra step of sending back an incentive might be an important indicator of negative reactions.

> *"It seems likely, however, that at least some respondents may feel unduly coerced into responding as a result of receiving multiple reminders. Despite an intensive search, no literature was found that has specifically investigated whether this is, in fact, the case."*
>
> *(Schirmer 2009 p. 130)*

Schirmer (2009) suggests that respondents should be informed that there will be reminders and ensure that participants can withdraw easily. Schirmer (2009) suggests further to stop sending reminders once a high response rate has been achieved. Bednall et al. (2010) have discussed how some compliance techniques border on the unethical when relying on deception or half-truths.

Dillman et al. (2009) discuss the conflict between survey sponsors who require high response rates and requirements by institutional review boards that undermine survey data quality. It has also been suggested that research ethical boards undermine the usefulness of surveys by for example requirements in cover letters (Grayson and Myles 2004) and by restricting the number of reminders (Howell et al. 2003). Requirements that respondents should sign an informed consent form have been shown to lower participation (Angus et al. 2003, Singer, 2008). Howell et al. (2003) claim that the ethical review process confers higher status on the rights of study participants than on the methodological demands of science. Martin and Marker (2007) argue that it is justified to use much stronger persuasive techniques in surveys than would be justified in more burdensome or higher risk research because of the high benefits of survey research in relation to the low risk involved for subjects. Grayson and Myles (2004) suggest that ethical review boards have no expertise in survey research and there is no reason to believe that survey researchers themselves are

incapable of designing ethical research. There is thus a conflict between respecting voluntariness for respondents and striving for reasonable response rates.

Consequences of different efforts to increase response rates

Strategies relying on persuasion and manipulation are widely accepted and used in many surveys. Some of these methods seem to balance on the edge of the ethically acceptable. The question is what consequences these efforts have. There have been concerns that reluctant respondents, who answer after several reminders or after persuasion, provide answers that are less thoughtful and lead to greater measurement error (Helasoja et al. 2002, De Rada 2005, Olson 2006). Even more important is the long-term consequences on the researcher–respondent relationship. In Riks-SOM participation was lower among individuals who were reached by a telephone reminder compared with the group who could not be reached and therefore got reminders by mail (Nilsson 2009). Making it harder for respondents to deny participation might foster distrust and skepticism about the good intentions of most surveys. Bergman and Brage (2008) found that pressuring respondents to participate can negatively affect cooperation propensities of future surveys. Schulman (2003) suggests that intensive refusal conversion methods may make respondents feel harassed when contacted again and again.

> *"At one level, this is a very effective strategy to reduce nonresponse. However, there may be a darker side of this strategy: I fear that we may burn bridges to respondents who are doubly annoyed at us and feel harassed..."*
>
> *(Schulman 2003 p. 452)*

Some respondents are very unlikely to be persuaded to cooperate and will be angry by reminders. In one study of refusal conversions 78% of the contacts led to a double refusal (Fuse and Xie 2007). Sudman (1985) suggests giving such respondents the possibility to identify themselves by

sending back the questionnaire with a note that they do not wish to participate. He suggests that this method might reduce the likelihood of future overt antisurvey behaviour.

Recent research has suggested that strategies to increase response rates might not be worth the extra cost and effort because the extra percentage units in response rates tend to consist of respondents from groups that are already well represented in the data and will therefore not decrease nonresponse bias (Rogelberg et al. 2003, Heerwegh et al. 2007, Van Ingen et al. 2009). Curtin et al. (2005) showed that efforts to increase response rates have mainly been successful in preventing further declines and that the effects have lasted very briefly. They conclude by stating "without better approaches to both contacting respondents and persuading them to be interviewed, the long-term future of telephone survey research does not appear promising." Curtin et al. (2005 p. 97). Thus, even if methods that rely on persuasion and manipulation can increase response rates in a specific survey, they do not seem to offer a long-term solution to the problem of decreasing response rates. As Kolar and Kolar (2008 p. 364) put it "It's hard to imagine that the use of compliance techniques like foot-in-the-door or multiple refusal conversion calls can be beneficial for long-term cooperative relationships."

Survey methodologists have often investigated nonrespondents' reasons for refusal: "There have been many studies to try to understand why people refuse to participate in surveys. If we could understand those reasons well enough, we might be able to do better at persuading people to participate in surveys" (Biemer and Lyberg 2003 p. 93). Some authors have remarked that there is a paucity of research on respondents who do take part and their motives for and experiences of participation (Singer and Bossarte 2006, Surkan et al. 2008). The aim of this thesis is to focus on the respondents' perspectives rather than the nonrespondents' (figure 2). Targeting respondents' own motivation might be an alternative approach to gain participation and to give respondents more positive experiences of their participation.

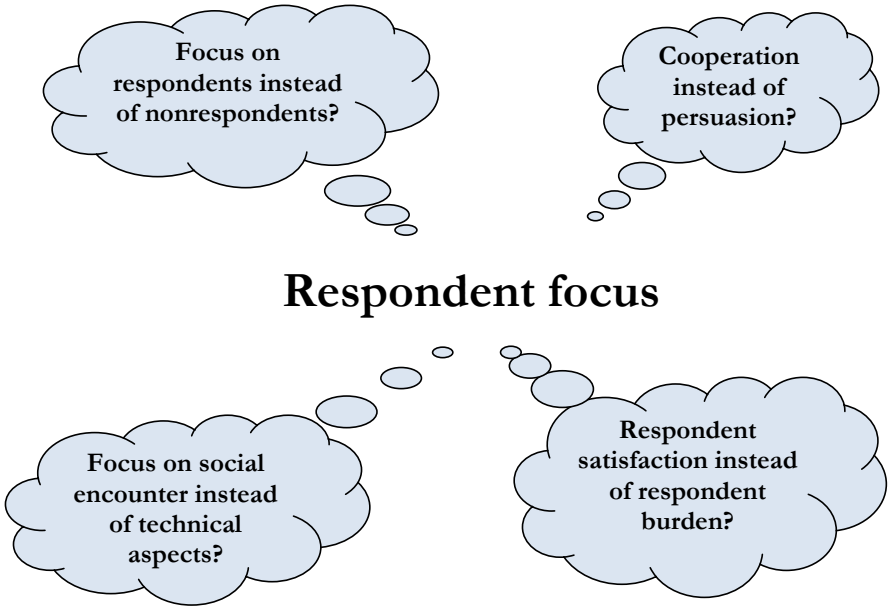


Figure 2. Possible ways to emphasize the respondent's perspective in the development of surveys.

Motivation theory

Motivation has been defined as the activation or energization to act (Ryan and Deci 2000a). Motivation is a broad area of research in psychology and includes several theoretical frameworks. Some aspects of motivation have been mentioned in survey research. Krosnick (1991) has discussed the relationship between motivation and quality of performance factors in terms of satisficing. Satisficing refers to response strategies aiming at completing the survey quickly and easily by for example choosing the first reasonable response option instead of reading all alternatives and choosing the optimal one. The opposite (optimizing) refers to the respondent performing each of the four steps of the cognitive process carefully and comprehensively. Krosnick (1991) suggests that task difficulty, respondent ability and respondent motivation are factors that influence satisficing.

Other researchers have discussed the role of incentives on respondent motivation (Moyer and Brown 2008, Peytchev et al. 2009). Cannell et al. (1981) showed that enhancing respondent motivation and reducing task difficulty increased data quality in interview surveys.

Self-Determination Theory

Self-Determination Theory (SDT) is a motivation theory that has been applied in many different areas of research, however, to the best of my knowledge SDT has not previously been applied to survey research.

SDT distinguishes between different types of motivation and posits that motivation to perform a task can vary from amotivation to intrinsic motivation (Ryan and Deci 2000a, Ryan and Deci 2000b, Deci and Ryan 2008). Amotivation refers to a lack of intention and motivation. A person with controlled extrinsic motivation complies with the request to get an external reward or to avoid negative feedback, embarrassment or guilt. A person with autonomous extrinsic motivation performs the task because of the value for him- or herself or for society. An intrinsically motivated person finds the task itself enjoyable and interesting.

The difference between autonomous and controlled motivation is central in SDT. Autonomous motivation comprises both intrinsic motivation and autonomous extrinsic motivation. When a person is autonomously motivated, they experience volition or self-endorsement of the task they perform as well as feelings of excitement, interest and enjoyment. When people are controlled, they experience pressure to think, feel, or behave in certain ways and this has been associated with anxiety and tension (Deci and Ryan 2000, Deci and Ryan 2008).

Ryan and Deci (2000b) and Deci and Ryan (2000) argue that three basic psychological needs facilitate intrinsic motivation; autonomy, competence and relatedness. Recent research suggests that motivational processes can be non-consciously activated and operate outside of consciousness to affect behaviours (Levesque et al. 2008). In one study by Levesque and Pelletier (2003) priming words for intrinsic motivation (autonomous, interested, challenge, spontaneous, involved, satisfied, volunteering, delighted,

competent, enjoying, mastering, absorbed) and extrinsic motivation (pressured, expected, obligation, constrained, demanded, avoiding, restricted, controlled, forced, competitive, evaluated, proving) were used for individuals who were then asked to solve puzzles. Individuals primed with the extrinsic motivation words found the puzzle task less interesting and spent less time working on the task compared with the intrinsically primed group. Priming people with autonomy orientation resulted in higher levels of intrinsic motivation, interest, enjoyment and perceived choice as well as better performance.

SDT suggests a relation between the type of motivation and the quality of performance of the task. In addition, autonomous motivation leads to better satisfaction in terms of perceived autonomy, competence and relatedness as well as interest/enjoyment, effort/importance, pressure/tension and value/usefulness as suggested in the Intrinsic Motivation Inventory Scale (Intrinsic Motivation Inventory (IMI)). Intrinsic motivation is regarded as superior to extrinsic motivation because it is associated with stronger commitment, better output and more positive experiences (Deci and Ryan 2000).

SDT has been applied in many different fields of research such as leisure activities (Watts and Caldwell 2008, Wilson et al. 2008), sport (Gillet et al. 2009, Podlog and Eklund 2009) and education (Lin et al. 2003, Niemiec and Ryan 2009). In the classroom setting, autonomy is supported by teachers minimizing any sense of coercion as well as maximizing the perception of having a voice and choice in the activities (Niemiec and Ryan 2009). The teacher should also provide students with a meaningful rationale for why the activity is important. Students' competence can be supported by optimally challenging activities along with appropriate tools and feedback to promote success. Students will engage only in activities that they can understand and master. Relatedness is associated with students feeling that the teacher likes, respects, and values them. It is further suggested that teachers who are controlled by pressure from above and standards will also be more controlling of the students.

Applying Self-Determination Theory to survey research

SDT could provide a theoretical framework for understanding motivation to participate in surveys. An application of SDT in a survey setting would mean that an amotivated person sees no value in the survey or does not have the competence needed to take part and therefore becomes a nonrespondent (figure 3). A person with controlled extrinsic motivation would agree to participate when incentives are offered or to avoid embarrassment from e.g. repeated reminders. A person with autonomous extrinsic motivation would participate because of the usefulness for him- or herself or for society. The intrinsically motivated person finds the questionnaire fun or interesting to fill in.

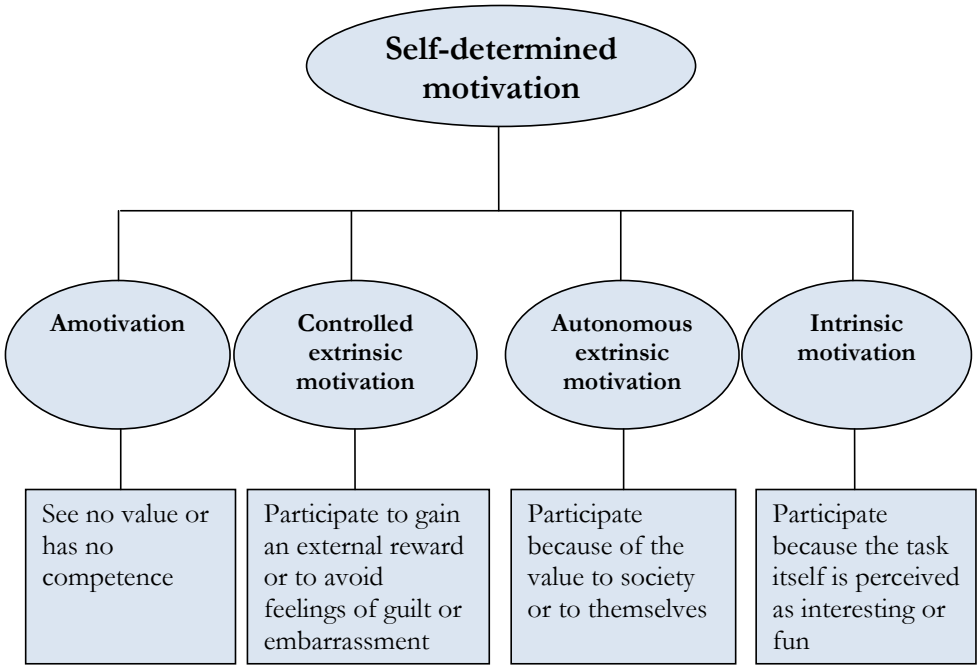


Figure 3. A simplified model of motivation according to Self-Determination Theory applied to survey participation.

Factors facilitating autonomous motivation (autonomous extrinsic motivation and intrinsic motivation) are autonomy, perceived competence and relatedness. The role of autonomy to increase motivation makes SDT an ethically attractive approach. When translating the classroom setting to a survey context, SDT suggests that autonomy would be supported by minimizing any sense of coercion and persuasion, which would mean reducing the number of reminders and stressing the voluntariness. Autonomy might also be stimulated by shifting control of the response process by including open-ended questions. Autonomy could possibly also be improved in data collection by informing respondents about how to decline participation. Perceived competence could be supported by a questionnaire that is not too difficult, but SDT also suggests that the task could be too easy if it does not present some challenge. Relatedness could be supported by the researcher showing respect for and valuing the respondent. When providing people with information about the value of an activity it is important that the value is described from their perspective and in a non-pressuring and respectful way (Moller et al. 2006).

The following text (somewhat shortened) was suggested by Sudman (1985) for a cover letter to professionals who were expected to be reluctant to respond.

> *We hope that you will be willing to return this questionnaire because we believe that the results will have important professional consequences. Nevertheless, we recognize that some of you will make a firm decision not to return it. If that is your decision, we respect it and do not wish to put any pressure on you to change your mind. Would you please return the questionnaire telling us that you do not wish to participate? If you have any comments that you wish to make, we shall read them carefully. We promise that we shall not send you the reminder material.*
>
> *Sudman (1985 p. 354)*

Compared with the text by Green (page 19) which leaves the respondent no control over reminders (other than participating) Sudman's text emphasizes both autonomy and relatedness.

Higher levels of motivation in the survey setting could lead to more active participation and stronger commitment to the task. Respondents would thereby be stimulated to give correct and truthful data. Cannell et al. (1981) found that a greater number of relevant health events were reported when a longer version of the question was used. They suggest one possible explanation to be that the long question indicated a serious intention and interest of the interviewer, which encouraged greater effort by the respondent. Smyth et al. (2009) similarly found that data quality in open-ended questions improved when clarifying and motivating instructions were used. Rogelberg et al. (2001) found that respondents' judgements of survey value and survey enjoyment were related to item response rates, following directions given in the questionnaire and expressed willingness to participate in additional survey research. According to SDT, higher motivation also leads to higher satisfaction among participants.

Many of the factors facilitating intrinsic motivation according to SDT are already well established in survey research. For example, making the questions as easy as possible to understand and providing a meaningful rationale for the survey have been shown to be important factors to improve survey response. Dillman et al.'s (2009) suggested respondent-friendly approach is in line with SDT's concept of relatedness built on a respectful communication. However, there are also important differences. According to SDT, incentives are not necessarily a token of appreciation and would only stimulate the lowest level of motivation (controlled extrinsic motivation). The same is valid for persuasion and coercion techniques. SDT even suggests that when such stimuli are presented to respondents with an initial high motivation to participate, such techniques might even undermine intrinsic motivation (Deci 1971, Deci et al. 1999). In practice, strategies to accomplish a respondent-friendly design in surveys are often used in combination with compliance and persuasion techniques, which according to SDT might have opposite effects on motivation.

Couper et al. (2008) have suggested three types of reasons for participating in a survey: altruistic (to be helpful), egoistic (e.g. to enjoy surveys, to learn something or to get money) and survey characteristics (e.g. interested in topic, in favour of the organization). In SDT, the specific reasons are grouped differently; enjoyment relates for example to intrinsic motivation, and participating for money relates to controlled extrinsic motivation.

Another difference is that former participation theories suggest that the decision to participate is a rational choice weighing the costs and benefits against each other. SDT suggests that motivation can be consciously or unconsciously activated (Levesque and Pelletier 2008) which raises the question whether survey researchers, sometimes, unintentionally facilitate lower motivation among respondents by using words which prime extrinsic motivation.

Motivation can be studied at different points in time. Before a survey request is presented, respondents have a general attitude to surveys. However, there is an important difference between attitudes to surveys in general and attitudes to a specific survey (Hox et al. 1995). These attitudes probably influence the initial motivation. Motivation can then change during the process of filling in the questionnaire, resulting in decisions to answer a specific question or not, to invest effort in answering and to decide to continue or to break off. After finishing the survey, motivation can be measured in terms of satisfaction with different aspects of the participation.

The post-experiment Intrinsic Motivation Inventory (IMI) scale has several items that seem to be applicable to survey research (Intrinsic Motivation Inventory (IMI), McAuley et al. 1989). For example *I think that doing this activity is useful* and *I enjoyed doing this activity* are similar to measurements of public opinions about surveys (Rogelberg et al. 2001, Stocké 2006, Loosveldt and Storms 2008). Other items of the IMI scale such as *I felt like it was not my own choice to do this activity*, *It was important to me to do well on this task* and *I would be willing to do this activity again because it has some value to me* could be important additional aspects in the survey application.

In summary, SDT provides a theoretical framework for studying motivation. The theory has many similarities with former participation theories but also important differences. SDT might be an additional source of inspiration to design surveys that are perceived as interesting and important to respondents.

Self-administered health-related surveys

Survey practice has gone through many changes in the last decades. The last decade has been called "the turbulent times" because of the fast-paced changes (Dillman et al. 2009). The introduction of cellular phones and a decline in the number of landline phones have rapidly changed the possibilities to conduct telephone surveys. Technical innovations have led to new developments such as web surveys, automated telephone interviewing systems and video-mediated interactions (Couper 2005, Conrad and Schober 2008, Couper 2008). However, self-administered surveys are still widely used in Sweden. It is a convenient method to collect data and it also has some advantages for the respondents because they can fill in the questionnaire at a time and place that suits them. There are also good possibilities for assuring privacy and anonymity. Because there is no interviewer present, the cover letter and the questionnaire itself must express the goals of the survey and the intentions of the researcher.

Self-administered questionnaires are widely used to collect data on health and lifestyle with the purpose of evaluating or planning health care and public health interventions. Questionnaires are also regularly used in epidemiologic research. Response rates have traditionally been high in those kinds of studies but are now suffering from declining response rates and intensified follow-up procedures (Carlsson et al. 2006, Ekholm et al. 2009, Galea and Tracy 2007). However, health-related surveys have the advantage of dealing with a subject of high relevance and interest to many people. These types of surveys may therefore have good opportunities to autonomously motivate people. Figure 4 presents a possible model (inspired by SDT) for respondent motivation in self-administered health-related surveys and possible effects of motivation on survey quality and respondents' experiences. The model includes examples of respondent factors, questionnaire factors and data collection factors that might affect respondent motivation.

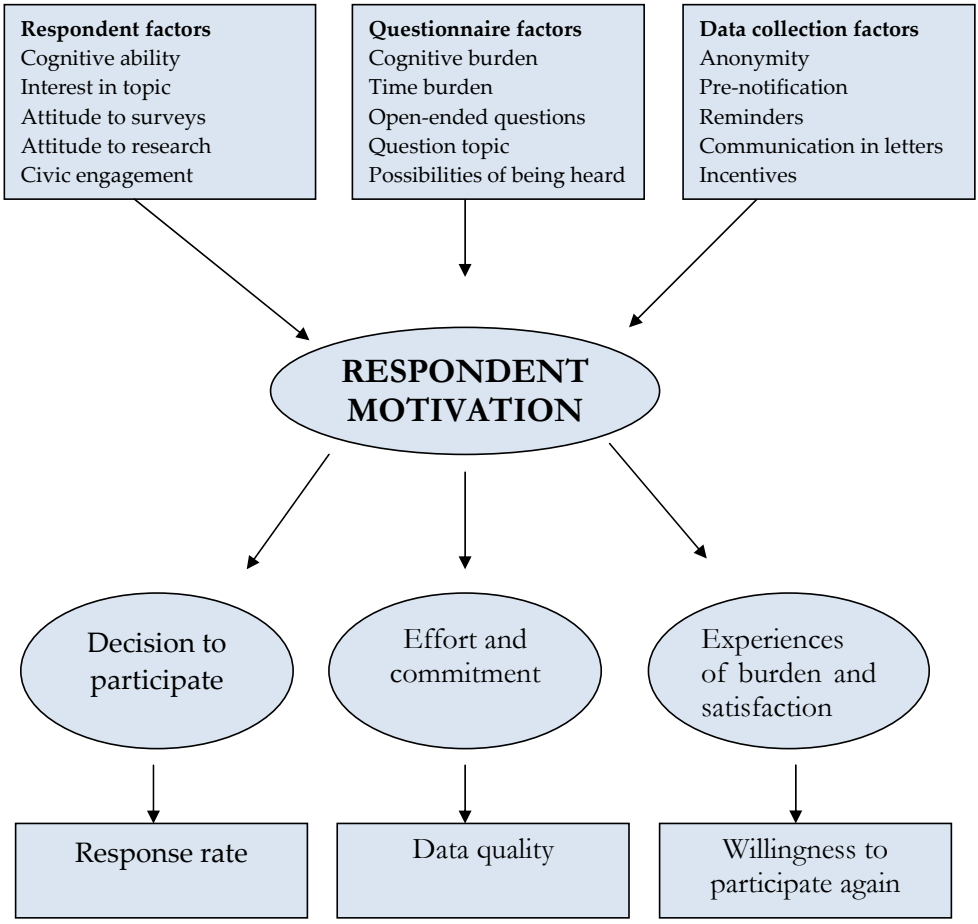


Figure 4. A possible model (inspired by SDT) for respondent motivation in self-administered health-related surveys and possible effects of motivation on survey quality and respondents' experiences.

OBJECTIVES

General aim

The aim of this thesis was to focus on the respondent's perspective in self-administered health-related surveys. Firstly, to learn more about positive and negative aspects that respondents experience when participating in surveys. Secondly, to study factors to increase motivation and possibilities to increase response rates in a way that promotes data quality as well as positive experiences among respondents.

Specific aims

- Investigate respondent satisfaction regarding two different questionnaires on health-related quality of life (paper I).

- Describe experiences of respondent burden and respondent satisfaction among participants in a self-administered health-related survey and relate these experiences to extrinsic or intrinsic motives for participation in surveys (paper II).

- Evaluate the use of lottery tickets as incentives in an epidemiologic control group in a survey about stress (paper III).

- Evaluate the effects of a survey design inspired by Self-Determination Theory on respondent satisfaction, response rate and data quality in a self-administered health-related survey (paper IV).

MATERIALS AND METHODS

This chapter describes the materials and methods of the four studies comprising the thesis (table 1).

Table 1. Overview of papers

Paper	Type of study	Study population	Analysis
I	Questionnaire study	392 patients in hospital intervention groups in 18 Swedish hospitals	Descriptive statistics McNemar's test Sign-test
II	Semi-structured qualitative telephone interview	30 participants in a longitudinal survey in the county of Östergötland (45–69 years)	Content analysis
III	Experiment in a self-administered survey	Random sample of 450 parents in the municipality of Stockholm	Descriptive statistics Chi-square test Survival analysis
IV	Experiment in a self-administered survey	Random sample of 16 440 inhabitants in the county of Östergötland (18–84 years)	Descriptive statistics Z-test

Paper I

Data collection

This study was part of the Health Outcome Assessment Project performed by the Swedish network, Health Promoting Hospitals (HPH). In 2004 all member hospitals were invited to participate in the project. A total of 18 out of the 23 invited hospitals chose to participate. Each hospital chose 1–4 patient intervention groups in their ordinary practice, each of which included around 20 patients. The most common intervention groups consisted of patient education groups with the goal of enhancing patients' capability to deal with and cope with their own disease and thereby improve their health-related quality of life (HRQoL). A total of 573 patients in 31 intervention groups responded to EQ-5D and SF-36 before and after the intervention (Brooks and De Charro 1996, Ware and Sherbourne 1992). This study consists of the 392 patients who completed both measurements and an evaluation form. The evaluation form included three questions concerning respondent satisfaction about each of the two questionnaires; if questions were easy/hard to understand, easy/hard to respond to and if the instruments were good/bad at describing the patients health in a comprehensive way. The patients were then asked if they perceived that health outcome assessment within routine health care would be valuable in the future, and if so, which of the two questionnaires they would prefer. An open-ended question giving the patients an opportunity to expand their answers concluded the evaluation form.

Analysis

A respondent satisfaction summary score was calculated from the three evaluation questions. In the analysis, the respondent satisfaction summary score was categorized into favouring EQ-5D, favouring SF-36 or equal. Descriptive statistics were given for the three individual questions as well as for the summary score. Differences between SF-36 and EQ-5D regarding the results of the evaluation questions were tested with the two-sided McNemar's test with Yate's continuity correction or two-sided sign-test

(when the number of discordant pairs was <10). Answers to open-ended questions were sorted into groups, referred to as categories. Each category was illustrated by quotations.

Paper II

Data collection

This study was made as part of the longitudinal study Life conditions, Stress and Health (LSH study). The aim of the LSH study is to analyse the effects of psychosocial factors on socioeconomic differences in health outcomes. The study population was randomly sampled from the catchment areas of 10 primary health care centres in the county of Östergötland. The first data collection, performed in 2004, included questionnaires, a visit to the primary health care centre for biological measurements (saliva, blood and urine samples) and a brief health examination. The participation rate was 62.5% and gave a final study population of 1007 participants aged between 45 and 69 years. The questionnaires included a broad range of items covering socioeconomic status, living conditions, psychosocial factors, stress, lifestyle and self-reported disease.

In the 2-year follow-up questionnaire in 2006 participants were asked if they would participate in an interview regarding the questionnaire and, if so, to provide a telephone number at which they could be reached. The questionnaire comprised 29 pages and approximately 450 questions. This questionnaire had a response rate of 79.5% and a total of 347 out of the 795 participants volunteered to take part in the interview. A stratified (health care centre, age group and gender) random sample of 30 participants were contacted by telephone, the study was described and an appointment for the interview was made if they still wanted to take part in the study. Four participants could not be reached and two declined participation. Written information about the study together with a new copy of the questionnaire was sent to the participants. Participants were asked to read through the questionnaire before the interview and mark

three questions that evoked positive feelings and three questions that evoked negative feelings, although they were allowed to report a smaller or larger number of questions if they wished. The interview was made by telephone and included questions about motives for participation in surveys and positive and negative aspects of their participation. The interviews were semi-structured and lasted, on average, 24 minutes.

Analysis

The open-ended question on motives for participation in surveys was used to categorize respondents into one of three motivational groups (with reference to SDT); participate to get a reward (controlled extrinsic motivation), participate because it is important or valuable to society (autonomous extrinsic motivation) and participate because it is an interesting or fun experience (intrinsic motivation). Data from the other two open-ended questions were analysed using qualitative content analysis with the aim of providing knowledge of the phenomenon of respondent satisfaction and burden. Meaning units were identified and grouped into categories that were then related to satisfaction and burden. Categories of satisfaction and burden were analysed across the three motivational groups.

Paper III

Data collection

This study was conducted as a randomized experiment among controls within a study that addressed stress in parents of children with cancer. The study included a self-administered questionnaire of five pages with questions on background and three scales assessing subjective perceptions of stress, burnout and strain. The study population consisted of a stratified random sample of 225 male and 225 female parents of at least one child (aged between 2 months and 16 years) in the municipality of Stockholm. The two strata were randomized separately into three subgroups: (a) no incentive; (b) a promised incentive of one lottery ticket to be received upon

reply; (c) a promised incentive of one lottery ticket to be received upon reply and an additional lottery ticket upon reply within one week. The questionnaire was sent together with a cover letter and a slip that recipients could return if they chose not to participate. Reminders were sent on three occasions to those who had neither returned the non-participation slip nor the questionnaire. All details of the data collection procedure and the questionnaire were identical for the three groups except for the information regarding the incentives.

Analysis

Response rates were compared with the chi-squared test for homogeneity and a *p*-value less than 0.05 (two-sided) was considered significant. The number of days until reply was used as the time to event in a survival analysis. Kaplan–Meier curves illustrated the time to response and the difference between the two curves was tested by the log-rank test.

Paper IV

Data collection

This study was made as part of a population-based self-administered health survey (Wenemark 2006, 2007, 2009). 16 440 inhabitants in the county of Östergötland (aged 18–84 years) were included in one of three experimental groups: (a) SDT design (SDT-derived questionnaire and data collection, *N*=2 490); (b) mixed design (standard questionnaire and SDT-derived data collection, *N*=499; (c) standard design (*N*=13 321).

The intention of the SDT-derived questionnaire and data collection was to combine several factors and build a design which could promote autonomous motivation among respondents. Autonomy was promoted, for example, by using open-ended questions in the questionnaire, by stressing voluntariness and by reducing the number of reminders in the data collection procedure. Perceived competence was stimulated by avoiding

items and scales with difficult or old-fashioned language. Another example of the intention of the design was to stimulate relatedness by using open-ended questions to show interest in the respondents' own expressions and by using a respectful communication without pressure.

Both questionnaires (SDT-derived and standard design) included 42 identical or nearly identical questions on background, health and lifestyle. The last page of the questionnaires included four evaluation questions and an open-ended question on respondents' opinions about the questionnaire. The standard questionnaire consisted of about 190 questions on 21 pages (including work situation, neighbourhood, height, weight, nicotine use, dental health and use of complementary medicine). The SDT-derived questionnaire consisted of about 90 questions on 11 pages (including country of birth, municipality of residence and availability of health care).

The standard data collection was performed by an agency for official statistics and included the initial mailing of the questionnaire, a thank you/reminder postcard and two postal reminders with a new questionnaire enclosed. The questionnaire was marked with an identification number and included linking with registry data on an individual basis. The SDT data collection was performed by the Centre for Public Health Sciences, Östergötland County Council, and included a pre-notification letter, the initial mailing of the questionnaire, one postal reminder with a new questionnaire enclosed. A shortened one-page questionnaire was used as an alternative to the second reminder. A separate response card with an identity number was sent together with the unmarked questionnaire.

Analysis

The three experimental groups were compared regarding the three outcomes: respondent satisfaction, response rate and data quality. The 1388 comments about the questionnaire were coded, grouped into categories and analysed by comparing frequencies. Respondent satisfaction was measured by the four evaluation questions, by the frequencies of the open-ended comments and by counting the number of registered telephone calls from angry or irritated respondents. Response rate were measured by day-by-day cumulative response as well as final response rate. Data quality was

measured by proportions of respondents who missed at least one page of the questionnaire, item nonresponse and by comparing estimated frequencies with calibrated estimates. Calibrated estimates were based on registry data on age, country of origin, municipality, marital status, education and occupation (Deville and Särndal 1992). Data quality measurements were compared at different response rate levels to detect changes during the data collection period. The results were standardized according to age and sex for the general population at the time of the study. Differences between proportions were tested using a two-tailed z-test for two independent samples (Fleiss and Levin 1981).

RESULTS

Paper I

Most patients regarded both SF-36 and EQ-5D as easy to understand, easy to respond to and that they both gave them the opportunity to describe their health in a comprehensive way. When the three questions were combined into a respondent satisfaction summary score, 67% of the respondents had an equal score for the two questionnaires, 20% were in favour of EQ-5D and 13% were in favour of SF-36.

Most patients stated no preference for which questionnaire they would prefer for use in routine health care (68%); 25% preferred SF-36 and 8% EQ-5D. Those in favour of SF-36 often mentioned that they regarded SF-36 as more comprehensive and that it had better response alternatives. Those in favour of EQ-5D mentioned that they found EQ-5D easier to respond to or that it was better than the alternative (SF-36).

Although EQ-5D was regarded as easier to understand and easier to respond to than SF-36, more patients chose SF-36 for use in routine health care (table 2). Among patients who rated SF-36 higher than or equal to EQ-5D on the respondent satisfaction score, very few preferred EQ-5D for use in routine health care. However, also among patients with a respondent satisfaction score in favour of EQ-5D, a number of patients still preferred SF-36. Thus, questionnaire length and ease of response were not found to be crucial arguments in choosing between SF-36 and EQ-5D for use in routine health care.

Table 2. Patients' preferences for SF-36 or EQ-5D for use in routine health care versus the respondent satisfaction summary score, among patients who were positive towards health outcome assessment

		Preference of instrument for use in routine health care			
	n	Prefer SF-36 % (*n*)	Prefer EQ-5D % (*n*)	No preference % (*n*)	*p* (SF-36 vs. EQ-5D)
All patients	210	25 (52)	8 (16)	68 (142)	<0.001
Respondent satisfaction summary score					
In favour of SF-36	34	47 (16)	3 (1)	50 (17)	<0.001
In favour of EQ-5D	34	26 (9)	32 (11)	41 (14)	0.82
Equal score	142	19 (27)	3 (4)	78 (111)	<0.001

Paper II

Respondents reported a broad spectrum of positive and negative experiences of their participation (table 3). Respondents described the importance of being able to contribute to results that are valuable, relevant and useful to society. They also expressed great responsibility for their data and that they wanted to give correct and truthful information (*If you don't understand the questions the results could be misinterpreted*). They reported experiences of cognitive burden when questions were difficult to understand or answer and they expressed a dislike for questions that were not applicable or that they found repetitive.

Respondents also stressed the importance of a trustful communication with the researcher, so that they could feel confident that data are interpreted, analysed and reported correctly. Respondents expressed that they do not want to feel manipulated or controlled (*Sometimes you realize that they are trying to find things out without the respondent noticing it*) and that they sometimes found questions to be offending or too personal. The respondents also commented on the importance for the researcher to show interest, to listen and to let them express themselves.

Table 3. Description of the categories of respondent satisfaction and respondent burden

Categories of respondent satisfaction	**Categories of respondent burden**
Contribution	Cognitive burden
(importance, relevance and usefulness)	*(difficulties to understand, retrieve, estimate and give answers)*
Responsibility	Unnecessary work
(give correct and truthful information)	*(not applicable or repetitive questions)*
Being heard	Distrust
(expression and being listened to)	*(control, manipulation and misinterpretation)*
Reflection	Offending questions
(reflection, insight and confirmation)	*(offending or too personal questions)*
	Distress
	(worry, anxiety or sadness caused by question)

Positive experiences of participation that was mentioned were reflections and new insights (*Positive when you get the questions as a help to reflect over your life and health*). Negative experiences reported included worry, anxiety and sadness caused by questions (*I don't have anyone. I think about it sometimes but now I saw it clearly when I answered the questions*).

The results also showed differences in experiences of satisfaction and burden depending on the respondent's primary motive for participation in surveys. Respondents with intrinsic motivation mentioned positive experiences of being heard and reflection. They also stressed the importance of a trustful communication. Respondents with autonomous extrinsic motivation showed responsibility for their answers in expressing concern about being able to give correct and truthful data. They were also concerned about cognitive problems. Respondents with controlled extrinsic motivation described negative experiences in terms of offending questions and distress but also valued positive reflection.

Paper III

The overall response rate for the three experimental groups was 65.3%. The response rate was highest in the no incentive group (69.3%) and lowest in the one plus one lottery ticket group (62.0%). The no incentive group had the highest response rate throughout the data collection period (figure 5).

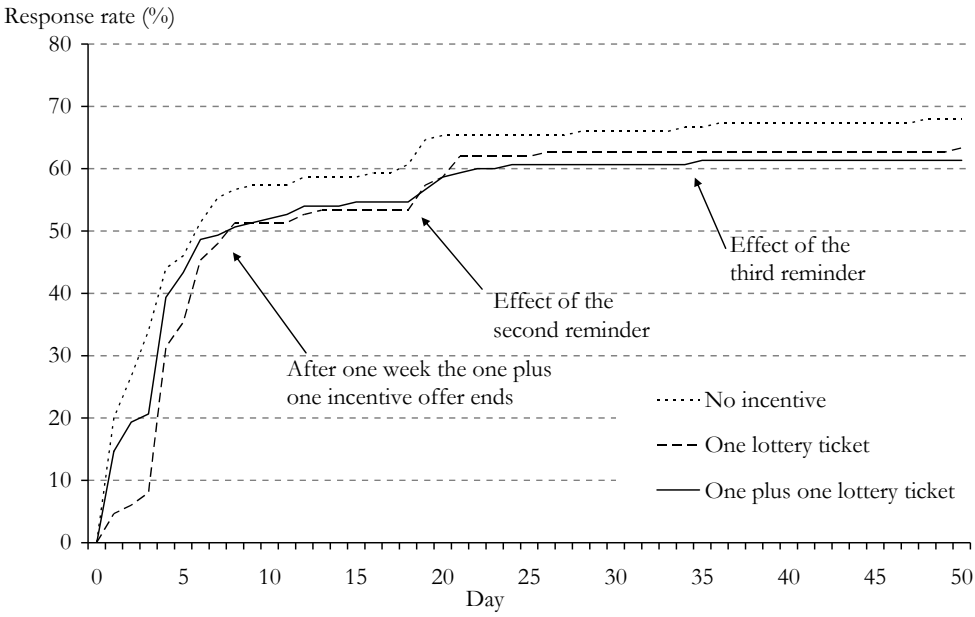


Figure 5. Day-by-day cumulative response rate for the three experimental groups.

The differences between the experimental groups were larger among men than women. Both the number of refusers (persons who returned the non-participation slip) and nonrespondents (who returned neither the slip nor the questionnaire) were higher in the incentive groups compared with the no incentive group. The survival analysis showed that the difference between the two response curves (one or two lottery tickets compared with no incentive) was significant (log-rank test p=0.04).

Paper IV

Respondents rated the SDT-derived questionnaire as easier, as having easier language and as more important than the standard design (table 4). There were no overall differences for rating the questions as interesting. However, men aged 18–29 years rated the questions in the SDT design as more interesting.

Table 4. Percentage of respondents who rated the questions as easy, having easy language, important and interesting

	Percentage of respondents (%)			Differences between designs (% units)		
	SDT design	Mixed design	Standard design	Data collection effect[a]	Questionnaire effect[b]	Total effect[c]
Questions were easy	42.9	28.7	27.6	1.1	14.2***	15.3***
Questions had easy language	76.8	61.3	62.2	–0.9	15.4***	14.5***
Questions were important	39.1	33.3	33.4	–0.1	5.8*	5.7***
Questions were interesting	25.6	27.8	24.7	3.1	–2.2	0.9

* $p<0.1$, *** $p<0.01$.

[a]Difference mixed design – standard design.

[b]Difference SDT design – mixed design.

[c]Difference SDT design – standard design.

Some differences between the two questionnaire designs were expressed in the comments. Comments about the standard questionnaire were more often that it was too long, that it took too much time to answer and that it included irrelevant questions. Comments about the SDT-derived questionnaire were more often positive and also included more suggestions on additional questions. There were less negative experiences with the STD

version, both in terms of negative comments and in terms of fewer registered telephone calls from angry or irritated respondents.

The response rate was higher for the SDT version throughout the data collection period (figure 6). The final response rate was 63.8% in the SDT design, 60.2% in the mixed design and 54.6% in the standard design. The effect of the data collection on the final response rate was 5.7 percentage units and was statistically significant overall, among men and in the 45–64 years age group. The effect of the SDT-derived questionnaire compared with the standard questionnaire was 3.5 percentage units and was significant only among women.

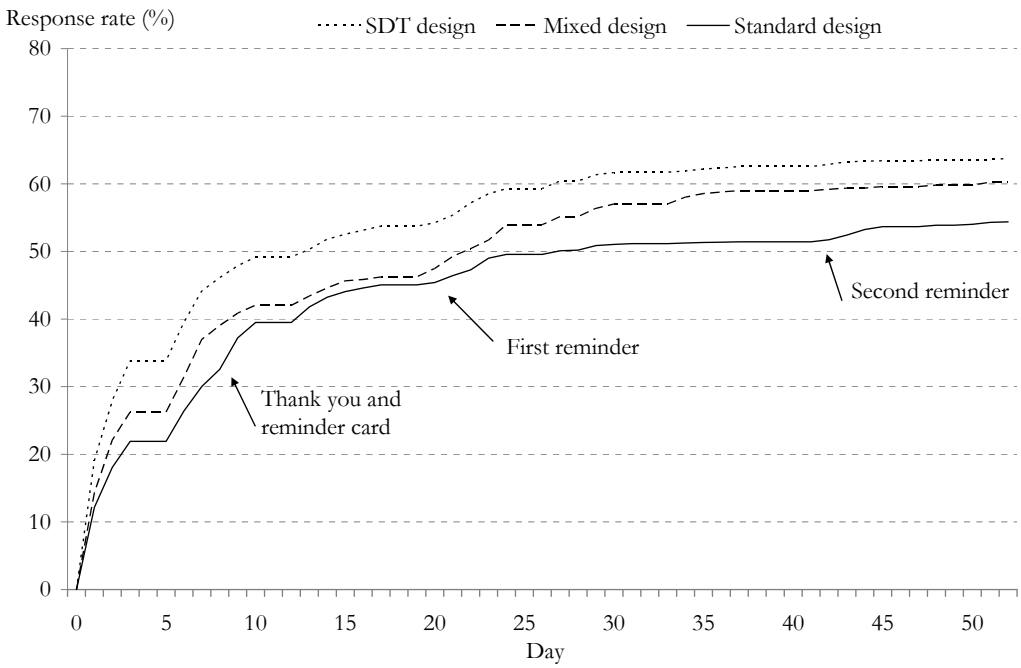


Figure 6. Day-by-day cumulative response rate for the SDT design, mixed design, and standard design.

Data quality was similar or better with the SDT design than with the standard design. When response rates were increased from 55% to 64% in the SDT design group, most estimates changed towards the calibrated

values which suggest that the last respondents added to a higher quality of data. With increasing response rates, the percentage of respondents who missed at least one page increased in the standard design group. There was no evidence of lower quality in terms of item nonresponse among late responders in the SDT design. Thus, the SDT-inspired design had a positive effect on respondent satisfaction, response rates and data quality.

GENERAL DISCUSSION

The aim of this thesis was to focus on the respondent's perspective in health-related self-administered surveys. This thesis expands the discussion of respondents' experiences of survey participation to include respondent satisfaction. It also extends previous research by applying a new theoretical perspective, SDT, to understand the role of respondent motivation.

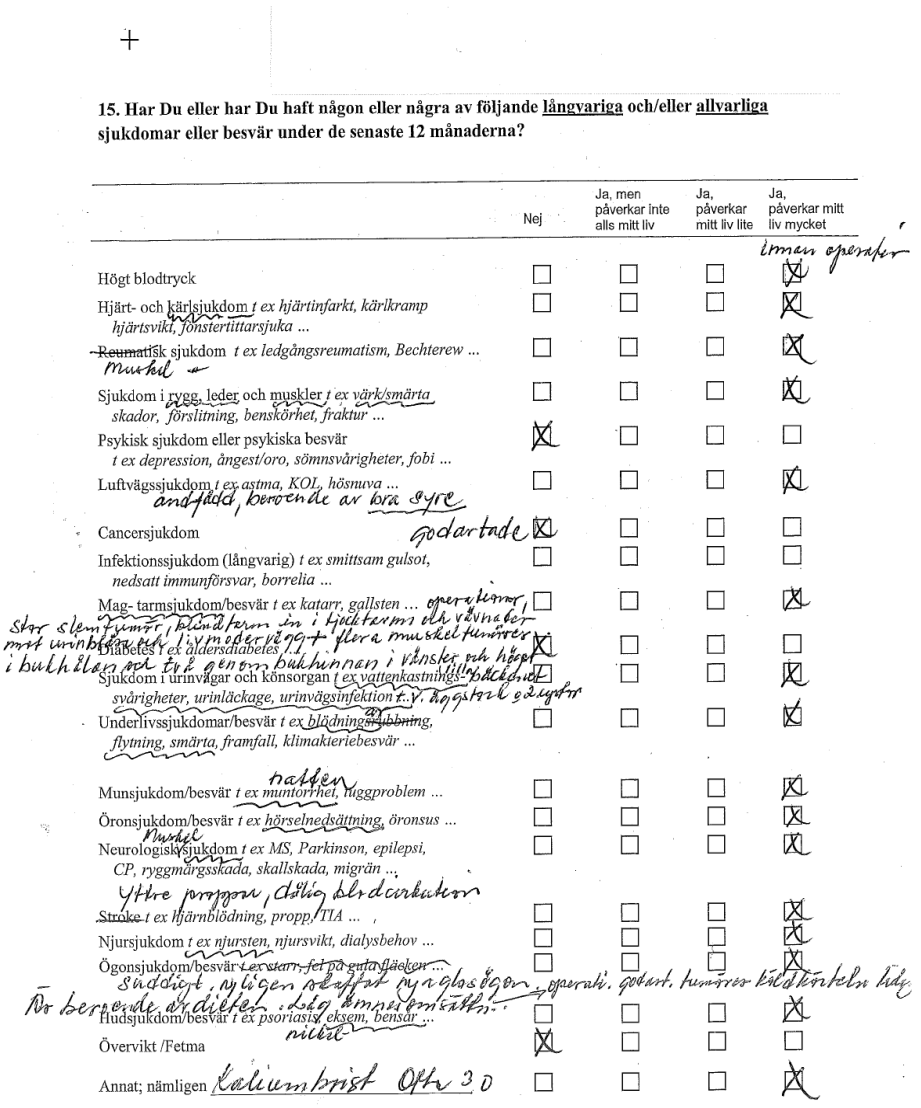
Experiences of respondent satisfaction and burden

The results of the studies in papers I, II and IV show many positive and negative experiences of survey participation. I have chosen to use the concepts of respondent satisfaction and respondent burden to describe these experiences. Some theories have used the terms costs/benefits to describe positive and negative aspects in the choice to participate or not. The concept of benefit is often defined in terms of extrinsic aspects such as incentives or benefits to society. An exception is the definition used by Fowler (2009), which includes both intrinsic benefits (enjoying the process of the interview or feeling that they contributed to a worthwhile effort) and more direct benefits (payment or prizes provided). However, the concepts of satisfaction and burden emphasize not only the choice of participation but also the perceived experiences when (and after) participating. It is for example possible to judge the benefit to society as high but still experience both burden and satisfaction from participation.

Experiences of respondent satisfaction

In the present studies respondents often mentioned the importance of contributing to valuable results that are useful to society. The most common argument in choosing between SF-36 and EQ-5D in paper I was that SF-36 was perceived as more comprehensive in giving a better picture of their health.

The results also showed the importance for respondents to be able to give correct and truthful information as well as to feel confident that data are interpreted, analysed and reported correctly. Many respondents showed a high level of responsibility for providing correct information (figure 7).



15. Har Du eller har Du haft någon eller några av följande långvariga och/eller allvarliga sjukdomar eller besvär under de senaste 12 månaderna?

	Nej	Ja, men påverkar inte alls mitt liv	Ja, påverkar mitt liv lite	Ja, påverkar mitt liv mycket
Högt blodtryck	☐	☐	☐	☒
Hjärt- och kärlsjukdom *t ex hjärtinfarkt, kärlkramp*	☐	☐	☐	☒
~~Reumatisk~~ sjukdom *t ex ledgångsreumatism, Bechterew ...*	☐	☐	☐	☒
Sjukdom i rygg, leder och muskler *t ex värk/smärta*	☐	☐	☐	☒
Psykisk sjukdom eller psykiska besvär *t ex depression, ångest/oro, sömnsvårigheter, fobi ...*	☒	☐	☐	☐
Luftvägssjukdom *t ex astma, KOL, hösnuva ...*	☐	☐	☐	☒
Cancersjukdom	☒	☐	☐	☐
Infektionssjukdom (långvarig) *t ex smittsam gulsot, nedsatt immunförsvar, borrelia ...*	☐	☐	☐	☐
Mag- tarmsjukdom/besvär *t ex katarr, gallsten ...*	☐	☐	☐	☒
Diabetes *t ex åldersdiabetes ...*	☒	☐	☐	☐
Sjukdom i urinvägar och könsorgan *t ex vattenkastning,*	☐	☐	☐	☒
Underlivssjukdomar/besvär *t ex blödning, flytning, smärta, framfall, klimakteriebesvär ...*	☐	☐	☐	☒
Munsjukdom/besvär *t ex muntorrhet, tuggproblem ...*	☐	☐	☐	☒
Öronsjukdom/besvär *t ex hörselnedsättning, öronsus ...*	☐	☐	☐	☒
Neurologisk sjukdom *t ex MS, Parkinson, epilepsi, CP, ryggmärgsskada, skallskada, migrän ...*	☐	☐	☐	☒
~~Stroke~~ *t ex hjärnblödning, propp, TIA ...*	☐	☐	☐	☒
Njursjukdom *t ex njursten, njursvikt, dialysbehov ...*	☐	☐	☐	☒
Ögonsjukdom/besvär ~~*t ex starr, fel på ögats linser ...*~~	☐	☐	☐	☒
Hudsjukdom/besvär *t ex psoriasis, eksem, bensår ...*	☐	☐	☐	☒
Övervikt /Fetma	☒	☐	☐	☐
Annat; nämligen Kaliumbrist Obs 3.0	☐	☐	☐	☒

Figure 7. Example of one respondent's answer in the standard questionnaire in paper IV.

In paper II respondents expressed great responsibility not only in answering single questions but also for relationships between questions that could lead to misleading conclusions (*You only know yourself if a traumatic event is relevant for stress and health*). However, this willingness to provide accurate information or provide more information than requested is not always appreciated by researchers, as discussed by Streiner and Norman (2003) in a chapter on "bias in responding".

> *The respondents' perspectives, however, are often quite different. They are often unaware that the individual items are ignored in favor of the total score. Even when told that their responses will be scored by a computer, it is quite common to find marginal notes explaining and elaborating their answers. Thus, it appears that respondents treat each item as important in its own right, and often believe that their answers will be read and evaluated by another person.*
>
> *Steiner and Norman (2003 p. 81)*

It is important to think about how surveys can benefit from this commitment, which leads us to the importance of communication between researcher and respondent. Sudman et al. (1996) suggest that a survey is a voluntary social encounter between strangers and therefore is subject to the same rules that govern social relations between strangers. But researchers have not often discussed what this means in modern survey design. The qualitative material in papers II and IV suggests aspects of communication that could be important to take into account in survey design. To establish a trustful communication, it is important to show interest in listening to the respondents and let them express, elaborate and explain their answers. With optical scanning we no longer read the paper questionnaires although that is one of the few possibilities for respondents to communicate with us (figure 7).

Positive experiences from respondents were also reflections about things related to the questions. In paper II respondents expressed that they gained new insights or learned something new. The results of paper II suggest that positive reflection is beneficial to respondents in health-related surveys and may play an important role in efforts to increase respondent satisfaction in

future survey design. In other studies, there have been somewhat surprised reactions to the fact that there were more positive reactions than negative (Jorm et al. 2007, Surkan et al. 2008). Several studies have shown that participants who experience distress can also experience their participation as positive (Scott et al. 2002, Jorm et al. 2007). The variety of aspects of satisfaction is especially hopeful because it may provide clues to a survey design that promotes positive experiences among respondents.

Experiences of respondent burden

The results of papers I, II and IV also show many different aspects of respondent burden. One type of burden is when respondents are asked questions that are not applicable or questions that are repetitive. A questionnaire with many "skip instructions" may give the respondent a feeling that the researcher is not interested in him or her. In the same way, respondents disliked questions that they could not answer or that did not seem relevant to them. Asking young people if they have glaucoma or asking old people about employment may increase the distance between researcher and respondent. The study on which paper IV was based, included an open-ended question on opinions about the questionnaire which has been thoroughly reported elsewhere (Wenemark 2009). Respondents who were for example healthy, young, old, living alone, retired, unemployed, self-employed, pregnant, students, widows, vegetarians and housewives commented that they did not seem to be the target group of the standard questionnaire. Taken to the extreme and excluding these groups, the questionnaire was suitable for a small group of middle-aged individuals (Wenemark 2009).

Respondents in paper II were also observant of questions that they considered manipulative or controlling. Repetitive questions were sometimes perceived as control questions to check the respondent's earlier answers, but may also give the respondent a feeling that no one cared to listen to the answers. The respondents also expressed irritation if they believed that the researcher was trying to find things out without the respondent noticing it. One textbook gives the advice to sometimes avoid face and content validity "…there are situations where face and content validity may not be desirable, and may be consciously avoided. For

example, in assessing behavior such as child abuse…" (Streiner and Norman 2003 p. 5). This advice is given without reflections on possibilities of how to ask parents if they abuse their children, without them noticing. Our results show that respondents are observant on these matters and disapprove of such methods. Kolar and Kolar (2008) found, similarly, that respondents are very sensitive to issues of fairness and ethics, and even minor unintended deceptions such as misinformation about the survey length can damage respondent cooperation. Other authors have addressed the importance of trust and respondent friendliness (Dillman et al. 2009, Snijkers et al. 1999). The consequences of manipulation and control have been less emphasized in the survey literature compared with, for example, time burden.

In papers II and IV some respondents reported that questions caused worry, anxiety and sadness. Common questions about health and lifestyle also caused such feelings. Old people, for example, worried about the future when answering questions of many different illnesses. In the study on which paper IV was based, there were also comments expressing distress *(I found these questions very heavy and sad for an old, lonely person like myself)* and *(The questions were sometimes formulated so they could influence the person who responds to become even more depressed and low-spirited in his(her) situation*) (Wenemark 2009). Distress was also caused by multiple reminders. Most respondents seemed to accept the first reminder but got annoyed about forthcoming ones. Respondents expressed irritation that they got new reminders even though each letter said it was voluntary (*It's tough to have it sent home three times with reminders that it is COMPLETELY voluntary).* They also expressed distress by not knowing how many more reminders there would be (*It was said to be voluntary – still reminders keep coming over and over again),* which shows the low level of control given to the respondents with this method (Wenemark 2009).

Participants' reactions have been investigated in trauma-focused research (Kreicbergs et al. 2004, Newman and Kaloupek 2004). Evans et al. (2002) found that a general impression seems to be that questionnaire-based research is risk-free to respondents but suggested three possible risks of harm: risk that the initial invitation or the content of the questionnaire causes worry or anxiety, and risk of disappointment if participants have expectations of receiving information or assistance. It has been shown that

distress is associated with reduced willingness to participate in future studies. Graaf et al. (2004) conclude from an earlier study (Graaf et al. 2000) that only 18% of the respondents who refused to participate in the second wave gave an unpleasant experience with the previous interview as the reason for their refusal. Researchers should be aware of possible distress that respondents may experience and an important question is if 18% is a high or a low number of refusals due to an earlier unpleasant survey experience.

Notably, worries about confidentiality or risk of disclosure (risk of deducing an individual's identity in a dataset that does not include personal identification number or name) were not common in any of the studies. Research has shown that issues of confidentiality or risk of disclosure assurances influence willingness to participate only when the data asked about are sensitive or when harm from disclosure is made explicit (Singer et al. 1995, Couper et al. 2010).

Can survey researchers learn from qualitative research?

The results in this thesis show more aspects of satisfaction and burden than usually discussed in survey research. The reason for these differences might be that many studies have focused on nonrespondents' reasons for refusing participation while this thesis is based on the experiences among respondents.

The experiences of satisfaction and burden shown in this thesis have many similarities to experiences that have been described among informants in qualitative interviews. Positive experiences discussed in qualitative research include giving the participant a voice, empowerment, healing and self-awareness (Hutchinson et al. 1994, Beck 2005). It has also been shown in qualitative research that respondents care about the outcome (sense of purpose) (Hutchinson et al. 1994).

Quantitative and qualitative methods are two fundamentally different research methodologies. They can answer different research questions, they involve different analyses and they are interpreted and presented differently. From the respondent's perspective, however, the step between

a commercial survey and a health-related research survey may be farther than between a quantitative health-related survey and a qualitative health-related interview. It may therefore be valuable to learn from the way informants are approached and valued as well as ways of cooperating with informants in qualitative research. It is common to see gratitude to informants expressed in acknowledgements of qualitative research papers. Furthermore, informants are sometimes asked to confirm transcripts and analyses, which give them opportunities to take responsibility for their answers. It gives them an important role in the research process that is seldom given to respondents in surveys. A future question is how we can increase the possibilities for respondents in surveys to take a more active part in the research process. Schulman (2003) suggests that by breaking down the wall between qualitative and quantitative we can move closer to our respondents.

Stimulating autonomous motivation in surveys

SDT is a framework for studying motivation that has an appealing positive view on motivation and seems theoretically applicable to survey practice. Applying SDT suggests that survey methodology should benefit from using tools not only to stimulate the lowest level of motivation (controlled extrinsic motivation) such as persuasion and incentives. However, it is unclear if it is a realistic goal to achieve the highest form of motivation (intrinsic motivation) among survey respondents. It seems more reasonable to strive for the highest possible level of motivation. I have therefore chosen to use the term autonomous motivation, which refers to both autonomous extrinsic motivation and intrinsic motivation.

Some survey design features used in this thesis

One way of improving autonomy in paper IV was to stress voluntariness and reduce the number of reminders in the data collection procedure. The data collection procedure was re-designed to be less persuasive and to give the respondents more control by informing them that there would be no further reminders. This procedure may have contributed to the lower number of irritated telephone calls at the end of the data collection period.

The number of angry calls was almost zero in the SDT-derived data collection despite the fact that the number of contacts in the two data collection designs was the same. There were also fewer written comments regarding feelings of being pressured by reminders.

Making the questions easier to understand and respond to is a well-known issue in survey design. Respondents in paper II commented that some of the complex scales were difficult and abstract. Several of these scales have old-fashioned or difficult language but are still used because they have been validated and because they offer comparability with other studies. The habit of reversing items was not appreciated by respondents who felt that the researcher wanted to check if they were following the questions. In the SDT-derived questionnaire in paper IV, complex scales and scales that use reversed items were therefore avoided.

The SDT-derived questionnaire was judged to be easier than the standard questionnaire but at the same time respondents to the SDT-derived questionnaire identified more questions that were lacking. This could imply that it is important not to make the questionnaire easy and short at the expense of meaningfulness and comprehensiveness, which is consistent with the findings of paper I. Similar to these results, Kim et al. (2006) found that several respondents identified important health-related aspects that were lacking, and they found items included that had no or negligible relevance. According to SDT, a task that is too easy can make it less stimulating (Niemic and Ryan 2009). Preston and Colman (2000) suggest that a scale that is too difficult to use, or too simple to allow respondents to express themselves, may make respondents frustrated and demotivated and decrease the quality of their response. Dillman et al. (2009) suggest that although longer questionnaires in general achieve lower response rates, limiting the questionnaire may also have the effect of making it seem less useful or important, and as a result the response rates do not improve. A very short and simple questionnaire may also reduce the possibilities to stimulate reflection and insight. Ganassali (2008) concludes that among motivated and involved respondents, the survey length does not seem to be an obstacle.

Content validity relates to how well the content of an instrument covers the construct it intends to measure. It has been pointed out that content validity usually relies on experts' judgements and not on respondents' perspectives (Carr and Higginson 2001, Yao et al. 2008, Dunderdale et al. 2005). The respondent might have other perceptions of content validity and it is therefore important to make the questions a compromise between the researcher's judgement of content validity and respondent-perceived validity.

Open-ended questions were used not only to improve autonomy for respondents in the response process but also to improve relatedness by showing interest in what the respondent wanted to say. Can open-ended questions be used to stimulate respondent interest and thereby increase involvement and propensity to cooperate? O'Cathain and Thomas (2004) believe that open-ended questions not only offer an opportunity for the respondents to voice their opinion but also may redress the power balance between the researcher and the respondent. They argue that a closed question always represents the researcher's agenda. Burke Draucker (1999) noticed that participants often provided more information than was requested. She tried to protect respondents by avoiding discussion of intimate details of abuse experiences. However, many respondents wanted to include such details to provide a meaningful narrative. Ong et al. (2006) had a similar experience and suggest that free text may be an appropriate tool for capturing the contextual issues that respondents consider relevant, thereby producing valuable additional insights.

Open-ended questions are often avoided in surveys because they are perceived as taking too much time to answer (Lynn 2008), generate more missing data than closed questions (Groves et al. 2009), have been shown to be related to breakoffs in web surveys (Crawford et al. 2001) and because of the costly coding process. Groves et al. (2009) also says that because coders are often in a separate unit in most organizations, there appears to be an increasing tendency to avoid the use of open-ended questions entirely.

Anonymity as used in the study in paper IV had the net effect of about two percentage units on the final response rate (data not shown in the paper). The questions in the anonymous version were also rated somewhat more

important by respondents. Anonymity reduces the risk of disclosure and may lead to less tension in respondents. The procedure of using a separate card with an identification number was described early in the literature (in old style Swedish).

> *"Om frågorna är ömtåliga, kan det vara lämpligt att göra rundfrågan anonym. Detta kan tillgå så, att man ber vederbörande dels sända in frågeformuläret utan namnuppgift, dels även – separat – posta ett brevkort på vilket meddelas, att formuläret besvarats. Man vet då vilka som svarat, men då namn och identitetsuppgifter saknas på formuläret, kan vederbörande känna sig fullt trygg med hänsyn till möjligheten, att man skulle kunna få reda på något om honom personligen."*
>
> *Hofsten (1948) p. 29*

This procedure has been shown to be a useful method to offer anonymity to respondents but still allow reminders to be sent to nonrespondents (Biggar and Melbye 1992). However, there is a risk of duplicates when respondents answer the questionnaire but fail to send the response card. Therefore in paper IV, the reminder questionnaire was printed on light beige coloured paper so that it could be easily separated from the original questionnaires when identifying possible duplicates. One duplicate was found and removed from the dataset. It has been shown that the degree of response anonymity during an interview influences respondents' willingness to reveal sensitive, personal information when measuring depression (Aquilino 1998) and eating disorders (Anderson et al. 2007). Others have shown no differences (Alvik et al. 2005). Durant et al. (2002) showed that anonymity enhanced the quality of self-reported sensitive behaviours. Although described very early in the literature, in Sweden, the practice of using an identification number on the questionnaire predominates in data collection practice, also in cross-sectional studies and studies that do not use identification for linkage with registry data.

If the goal is to persuade unwilling respondents to participate it may be reasonable, also from an SDT perspective, to use factors that stimulate the lowest level of motivation (controlled extrinsic motivation). Incentives of

value to the respondent could, according to SDT, be efficient in making an amotivated person comply with the task of taking part in the survey. Most researchers advise against sending incentives only to the nonrespondents as part of the follow-up, because this could teach respondents to await a possible incentive later during the data collection period. It is also ethically questionable to reward only those who do not answer to the first invitation. There remains the alternative of sending incentives (prepaid or promised) to all respondents. Prepaid cash incentives have been shown to be most efficient (Church 1993, Ulrich et al. 2005). The question is what influence incentives have on respondents who already have a higher level of motivation to participate. Several health-related studies have reported tendencies of negative effects on response rates with the use of incentives (Blomberg and Sandell 1996, Coogan and Rosenberg 2004, Harris et al. 2008). The question has been raised whether factors influencing the respondent in a negative way are activated when incentives are offered in health-related surveys (Blomberg and Sandell 1996, Coogan and Rosenberg 2004, Robertson et al. 2005, Nakash et al. 2008). According to SDT incentives might undermine intrinsic motivation, which is a possible explanation for the results in paper III (Deci 1971, Deci et al. 1999).

Motivating different respondents

In paper II respondents with different motivation to participate stressed different aspects of satisfaction and burden. In paper I many women above the age of 65 years found SF-36 difficult to understand and respond to. Older people may have special problems in answering questionnaires (Hayes et al. 1995, Mallinson 1998) or special preferences on response formats (Castle and Engberg 2004).

Because different respondents value different aspects of satisfaction and burden, it is reasonable to believe that people may also react differently to stimuli aiming at increasing motivation. The results of paper IV show that men and women reacted differently to the different versions; women appreciated the re-designed questionnaire and men appreciated the re-designed data collection. The results of paper III suggest that incentives might undermine motivation among highly motivated respondents. Is it

then possible to stimulate respondents with different characteristics and different motivation to participate within a single design?

Peytchev et al. (2009) noted, in an experiment on web surveys, that people who broke off were not inattentive respondents but respondents who seemed to spend time and tried to answer the questions carefully. This could be an example of a group of motivated respondents who experienced burden in terms of difficult questions or questions that they could not answer truthfully despite their effort. This finding needs further attention because we want to keep respondents who try to answer questions carefully in the survey.

Effects of increasing motivation in surveys

With reference to SDT, factors to increase motivation should, in the survey setting, influence the decision to participate (resulting in higher response rate), effort and commitment (resulting in better data quality) and experiences of participation in terms of satisfaction (resulting in positive attitudes to upcoming surveys and willingness to participate again). Stocké (2006) showed that respondents with more favourable evaluations of surveys had lower values on all kinds of nonresponse indicators. Stocké and Langfeldt (2004) found that subjects who judged their last interview to be too long, and the required time and effort for completing the questionnaire as too much, had more negative evaluations of surveys. This thesis has shown that attempts to use SDT as an inspiration for survey design can lead to improved response rates and respondent satisfaction with the same or improved data quality.

So far it seems that increasing motivation will have only positive effects, but what are the drawbacks? With declining response rates researchers have become more and more interested in the relation between response rates and nonresponse bias. Several authors have shown that response rate is not a good predictor of the magnitude of nonresponse bias in a specific study (Curtin et al. 2000, Keeter et al. 2000, Groves 2006, Groves and Peytcheva 2008). It has been argued that methods to gain respondent cooperation should vary across respondents (Groves 2006, Groves et al. 2006, Peytchev

2009). To reduce nonresponse bias, it would be more successful to use factors that would lead to participation among respondents with low motivation. Peytchev (2009) also suggests that a theory-driven approach should place more effort on people who refuse to participate than other groups such as non-contacts. Barón et al. (2009) have shown that incentives improved response rates primarily amongst individuals least likely to respond and equalized response rates across different socioeconomic groups. In paper IV data quality were similar or improved with the SDT design. However, it is important to study the effects on nonresponse bias in future studies.

According to the reasoning about nonresponse bias, survey researchers do not need to worry very much about the willing respondents. However, since response rates keep decreasing, some of the respondents who were willing a few years ago must have become nonrespondents, which shows the importance of also focusing on our current willing respondents. What happens to those interested respondents if we use factors known to primarily stimulate people with no motivation to participate? An uninterested person will appreciate the shortest possible questionnaire and may demand an incentive to comply with the task. The result of this thesis has shown that a questionnaire can be judged as too short by committed respondents and incentives may have contradictory effects on the response rate among highly motivated respondents. Designing surveys that apply primarily to persons with no or low motivation might be effective in terms of reducing nonresponse bias, but at the same time there is a risk of lower motivation among the initially highly motivated people. This may highlight an important decision for future surveys: to strive to motivate the reluctant or strive to keep the willing respondents. In a longitudinal survey, this dilemma is apparent because it is of great importance to get different kinds of respondents into the respondent pool as well as motivating all kinds of respondents to continue responding in future waves.

Measuring and reporting respondents' experiences could be used as an important quality indicator along with response rates and measurements of data quality. Some of the items of the IMI scale (Intrinsic Motivation Inventory (IMI), McAuley et al. 1989) are closely related to experiences of satisfaction and burden in papers II and IV. There are also similarities with suggested measurements of general attitudes to surveys (Goyder 1986,

Loosveldt and Storms 2008). Table 5 shows examples of items from the IMI scale and the Opinion about Surveys Scale along with experiences of satisfaction and burden found in papers II and IV. Some of the measurements suggested include items that specifically relate to commercial surveys, which many people find quite different from research surveys. It is possible that experiences of satisfaction and burden, together with proposed measurements of satisfaction according to SDT and proposed measurements of survey attitudes, can be combined into an evaluation instrument for measuring respondent satisfaction in specific surveys. Similar questions may also be used in cognitive interviews to include more respondent satisfaction aspects at the design stage of a survey.

Table 5. Examples of items in the IMI scale, aspects of satisfaction and burden in papers II and IV and examples of items in the Opinion about Surveys Scale in relation to the seven domains of the IMI scale

IMI scale	Example of items in IMI scale[1]	Examples of experiences of satisfaction and burden in papers II and IV	Examples of items in Opinion about Surveys Scale[2]
Perceived choice	I participated in this survey because I wanted to I felt like it was not my own choice to participate	I could express myself I felt researchers tried to control my answers I felt participating wasn't voluntary	
Relatedness	I felt I could trust the researchers	The researchers were interested in listening to me The questions were not for people in my situation I felt manipulated by questions The answers will probably be misinterpreted	Researchers ensure at all times that survey results are accurate
Perceived competence	I am satisfied with my performance in this survey This was a task that I couldn't do well	Questions were easy Questions were difficult to understand and answer	The questions of some surveys are too difficult
Interest/ enjoyment	I would describe participating as very interesting I thought this was a boring activity	Questions made me reflect on my health and lifestyle Questions gave me some new insights Questions were interesting	Participating in surveys is fun Participating in surveys can be interesting
Effort/ importance	It was important to me to do well at this task I didn't put much energy into this	There were too many questions I felt as if I answered the same questions several times	Participants in surveys do their best to answer as truthfully as possible Most surveys take up a lot of time
Pressure/ tension	I felt very relaxed in participating I was anxious while answering the questions	Some questions were too personal Questions caused worry, anxiety or sadness	Surveys tend to include questions that are too personal
Value/ usefulness	I think that participating is useful for society I believe participating could be of some value to me I would be willing to participate again	I could give correct and truthful information This survey will be useful Questions were relevant Questions felt meaningless	Surveys are useful ways to gather information Surveys are important for science

[1] Examples of items from the IMI scale applied to the survey setting (Intrinsic Motivation Inventory (IMI)).

[2] Examples of items from the Opinion about Surveys Scale (Loosveldt and Storms 2008).

METHODOLOGICAL DISCUSSION

Limitations

When studying respondents in surveys it is difficult to make perfect studies. In this thesis I have tried to embed experiments and interviews into the original design of real studies. Planning research within research in this way often involves limitations. There are usually factors that cannot be changed or manipulated in an experimental design because of the design of the original study. It would also be unethical to let people respond to a questionnaire that you believe is less satisfying than a re-designed version. The standard questionnaire in paper IV is therefore probably more respondent-focused than a real standard. For example, we included open-ended questions in the standard questionnaire as well to give all respondents an opportunity to express themselves.

There is a difficulty when making surveys on surveys because there is a risk that the respondents have more positive attitudes to surveys compared with the nonrespondents (Loosveldt and Storms 2008). Participants in paper IV had initially accepted to participate in a health-related study conducted at the local primary health care centre i.e. not a "traditional" survey. According to the first question in the interview the study population included people who usually participate in surveys as well as people who seldom do so. It is possible that the respondents in paper II and IV emphasized different aspects of satisfaction and burden compared with the general population. It is also possible that patients, who completed the questionnaires and the evaluation form in paper I, are more positive towards questionnaires and health measurements than patients in general. However, in this thesis, the experiences of the positive respondents have been of great importance because they are the respondents we want to keep as respondents in future surveys.

Some of the studies in this thesis are based on small samples. Paper II is based on 30 interviews. The sample in paper III, although rather large as an epidemiologic control group, is quite small in an experimental context. Paper IV is based on a large sample but the three experimental groups differ in size. The sample for the mixed design group consists of 499 persons compared with the sample for the standard design group of 13 321 persons. This makes the statistical power for comparisons across the three groups different.

Some aspects of measurements in this thesis must be mentioned. In paper II the categorization into three motivational groups based on a single question is crude. Also the four evaluation questions in paper IV, although similar to items in the IMI scale, have not been validated in their current form. Also the IMI scale itself has been claimed to have conceptual and operational weaknesses in assessing levels of intrinsic motivation (Markland and Hardy 1997).

In paper IV, the three designs differed in several ways, which makes it impossible to draw conclusions on the effect of specific factors. Future research is needed to disentangle the role of the individual factors. Comparisons with calibrated values in paper IV is not ideal, but was the best available substitute for the true estimates.

Generalizability

The focus of this thesis has been on self-administered health-related surveys in Sweden. It is difficult to assess generalizability to other modes, topics and countries.

The decision to participate or not differs between different survey modes. In a telephone survey, the respondent usually makes the decision in a few short moments based on information given by the interviewer. When participants have agreed to participate, they usually complete the interview. In self-administered questionnaires, the respondents can look at the questions before they make their decision and they can break off whenever they want.

The experiences of satisfaction and burden in papers I and II are closely related to findings from qualitative interviews. However, this does not mean that the results are applicable to quantitative interviews with highly standardized questions and answers. It is possible that positive effects of reflection play a more important role in self-administered questionnaires because the respondents have more time to think about questions.

Topical interest has been shown to affect response rate (Groves et al. 2004). Because health and health care issues are relevant to many people, health-related surveys may have the advantage of high interest and willingness to contribute to medical research. It has therefore been suggested that health-related surveys should be studied separately when evaluating the effect of nonresponse reduction strategies (McColl 2007).

All four papers are based on samples of Swedish inhabitants. Paper I is based on patients at 18 hospitals across Sweden. Papers II and IV are based on samples from Östergötland county and paper III is based on a sample from the municipality of Stockholm. Östergötland has sometimes been referred to as a miniature Sweden because it has large cities and small cities as well as rural areas. In national surveys, the county of Östergötland often has response rates near the national average and Stockholm often has lower. The results are probably fairly representative of the Swedish situation.

Qualitative method

Because this thesis is based mainly on quantitative methods, I have generally followed quantitative methodological terms. However, it is important to give a few methodological comments on the qualitative parts. I chose to do qualitative interviews to get a deeper understanding of the experiences of respondent satisfaction and burden in paper II. The answers in the interviews were usually thoughtful and got deeper into the real experiences of the respondents than would have been possible by using questions in a questionnaire.

Telephone interviews have the advantage that the respondents can be interviewed at home, in the same environment as they presumably had filled in the original questionnaire. A disadvantage of telephone interviews is that it is not possible for the interviewer to see body language or facial expressions. Because we did not intend to analyse detailed transcripts, the interviews were not audio-recorded. As the answers were often one or a few short sentences we found that it worked well to write down the answers during the interviews.

The analysis process in this study follows conventional content analysis as described by Hsieh and Shannon (2005). This method uses the direct information from data without imposing preconceived theoretical perspectives. The analysis starts with the aim of describing a phenomenon when existing theories are limited. Most concepts used in the analysis follow Graneheim and Lundman (2004). They suggest use of the concept *meaning unit* as the constellation of words, sentences or paragraphs containing aspects related to each other through their content and context.

Trustworthiness was increased in the qualitative analysis (paper II) by all authors being involved at different stages of the analysis. As a final evaluation of the analysis, all authors read all meaning units in each category. Meaning units are used as illustrative examples in the presentation of the results to give the reader the opportunity to trace the categories back to the interview documentation (Patton 2002).

Ethical considerations

Throughout the thesis I have tried to keep methods on a solid ethical basis. There are obvious problems, for example, in re-designing a questionnaire and then letting some respondents answer the original version which you believe to be less satisfactory for the respondents.

In paper II the respondents were invited to the interview on the last page of a questionnaire. They were contacted on the telephone number they had provided and given another option to refuse participation after hearing the

detailed description of the study. The decision to drop out, in two cases, was not questioned.

In paper III only promised incentives was used for ethical reasons. Three postal reminders are too many according to the minimal effect on response rates of the third reminder (figure 5). On the other hand, respondents were given an opportunity to return a non-participation slip to avoid reminders.

In paper IV the SDT design succeeded in reducing the number of telephone calls from angry or upset respondents to almost zero. This was probably the result of the non-offensive follow-up strategy. No refusal conversion attempts were used in any of the designs.

CONCLUSIONS

Focusing on the respondents' perspectives has provided important new knowledge. The results show a broad spectrum of positive and negative aspects of survey participation. The results also support SDT as a useful theoretical framework for studying motivation in survey research and for being an interesting additional source to provide ideas on how to design surveys with potential to motivate respondents.

- Questionnaire length and ease of response were not found to be crucial arguments in choosing between two health questionnaires for use in routine health care. Instead, the most common motives for the respondents' choice concerned aspects of the comprehensiveness of the questions.

- Respondents expressed a broad spectrum of respondent satisfaction and respondent burden. These experiences differed depending on the respondents' primary motive for participation in surveys.

- The use of lottery tickets as incentives in a self-administered survey among parents may be less valuable or even harmful as a means of increasing response rates.

- A survey design inspired by SDT yielded higher satisfaction among respondents and improved response rates with similar or better data quality compared with a standard design.

- The results suggest that it is possible to improve response rates in a way that promotes data quality as well as positive experiences among the respondents.

SAMMANFATTNING PÅ SVENSKA

Urvalsundersökningar är en viktig informationskälla i ett modernt samhälle. De bidrar till att få information från exempelvis medborgare, anställda, hushåll, patienter, konsumenter och företag. Urvalsundersökningar är också ett sätt att lyssna på medborgarna i ett demokratiskt samhälle.

För att resultaten ska bli så tillförlitliga som möjligt är det viktigt att så många som möjligt svarar. Svarsfrekvensen i urvalsundersökningar har dock minskat med åren vilket kan leda till lägre kvalitet på data. Sjunkande svarsfrekvenser är därför ett hot mot användbarheten av resultaten och kan minska förtroendet för undersökningarna. Många forskare har därför studerat anledningarna till varför en del väljer att inte delta i urvalsundersökningar och de har försökt motverka de sjunkande svarsfrekvenserna med allt intensivare uppföljningsmetoder. Sådana metoder har ibland visat sig ge negativa reaktioner bland dem som tillfrågas och kan möjligen leda till mindre vilja att delta i framtida studier. Även om dessa metoder har visat sig effektiva för att höja svarsfrekvensen i enskilda studier verkar de inte vara en långsiktig lösning på problemet med sjunkande svarsfrekvenser.

Få studier har undersökt faktorer som kan gynna motivationen, inte enbart för att delta, utan också för att bli engagerad och besvara frågorna noggrant. Denna avhandling fokuserar på de svarandes (dvs. respondenternas) perspektiv i hälsorelaterade enkätstudier. Syftet var att undersöka positiva och negativa erfarenheter av att delta i enkätstudier, studera faktorer som kan öka motivationen och studera möjligheterna att öka svarsfrekvensen med metoder som också gynnar kvaliteten på data och skapar positiva erfarenheter för de svarande. Self-Determination Theory (SDT) är ett teoretiskt ramverk för att studera motivation. Enligt SDT kan motivation variera från amotivation (avsaknad av motivation) till intern motivation. Intern motivation är förknippad med starkare engagemang, bättre resultat och mer positiva erfarenheter.

Artikel I är en deskriptiv studie om patienters synpunkter på två hälsorelaterade enkäter. Patienter i 20 interventionsgrupper vid 18 svenska sjukhus fick besvara de två enkäterna före och efter interventionen. Resultaten visar att frågeformulärets längd och hur lätt det var att besvara frågorna inte

var avgörande argument i valet mellan de två hälsoenkäterna för rutinmässig användning inom vården. Istället var de vanligaste motiven för valet olika aspekter av frågornas bredd och förmåga att ge en helhetsbild av hälsan.

Artikel II är en kvalitativ analys av data från telefonintervjuer med respondenter som besvarat en hälsorelaterad enkät i en urvalsundersökning i Östergötland. Resultaten visar många olika aspekter av tillfredsställelse och börda. Tillfredsställelse innefattar till exempel vikten av att kunna lämna korrekt och sanningsenlig information som är användbar för samhället. Respondenterna uttryckte också vikten av att forskaren visar intresse att lyssna på dem och de uttryckte uppskattning för frågor som leder till reflektion och nya insikter. Respondentbörda inkluderar till exempel upplevelser av att bli manipulerad eller kontrollerad av forskaren och oro, ängslan eller sorgsenhet som orsakas av frågorna. Erfarenheterna av tillfredsställelse och börda skiljde sig åt för respondenter med olika motiv för att delta i urvalsundersökningar.

Artikel III är en experimentell studie i en hälsorelaterad enkätstudie riktad till ett slumpmässigt urval av föräldrar i Stockholms kommun. Resultaten visar att lotter som belöning är mindre lämpligt eller till och med negativt för syftet att öka svarsfrekvensen bland föräldrar. En möjlig förklaring är att belöningar kan underminera motivationen hos deltagare vars motivation redan är hög.

Artikel IV är en experimentell studie inom ramen för en hälsorelaterad enkätstudie till den vuxna befolkningen i Östergötland. I studien jämförs två olika enkätdesigner och två olika datainsamlingsmetoder. Den SDT-inspirerade designen i denna studie gav högre respondenttillfredsställelse och bättre svarsfrekvens med samma eller bättre datakvalitet jämfört med standarddesignen.

Att fokusera på respondenternas perspektiv gav viktig ny kunskap. Resultaten visar ett brett spektrum av såväl positiva som negativa aspekter av att delta i en enkätundersökning. Resultaten stödjer SDT som användbart teoretiskt ramverk för att studera motivation i urvalsundersökningar och som en ytterligare källa till idéer om hur enkätstudier kan designas med potentialen att motivera respondenterna. Resultaten talar för att det är möjligt att öka svarsfrekvensen i enkätstudier på ett sätt som samtidigt bidrar till en god datakvalitet och positiva erfarenheter för respondenterna.

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