

NETHERLANDS
JOURNAL OF
PSYCHOLOGY

VOLUME 67, NUMBER 2, NOVEMBER 2012

HIV-prevention interventions

Psychological care in cancer patients
and their carers

Volume 67/number 2/November 2012 Netherlands Journal of Psychology

Editorial Policy

The *Netherlands Journal of Psychology* publishes original articles of high quality, including empirical articles, review essays on selected books, theoretical and methodological papers in any area of psychology, as well as ongoing commentaries and discussion, and short reports on the validation of psychodiagnostic instruments and related methodological tools.

The *Journal's* focus is on empirical and conceptual studies that contribute to the theoretical explanation of human behaviour and experience. Manuscripts can deal with human development, social processes and the social perspective of human behaviour, psychopathology, forensic psychology and psychiatry neuroscience, psychophysiology, philosophy of mind, the computational approach, emotion, cognition (including attention, perception, and memory), decision-making, human performance, educational psychology, health, selection and assessment and human behaviour in organisations, selection and assessment. Any other manuscripts that may be of importance to those involved with psychological research are welcomed. Manuscripts should be written to the professional and academic readership.

It is the *Netherlands Journal of Psychology's* policy to publish about recent developments in psychology and related fields. It is also the editors' policy to regularly focus on recent developments in psychology in the Netherlands. In particular, authors may be invited to contribute to special issues.

The *Netherlands Journal of Psychology* will help to focus the interest of psychologists, and others professionally interested in the field, on information about developments in a wide area of specialist research activities and results of empirical and theoretical work in the field of psychology.

The *Netherlands Journal of Psychology* offers specialists the opportunity to publish their findings to a broad audience that is scientifically interested in psychology.

The *Netherlands Journal of Psychology* aims at offering a continuous forum for intellectual discussion and transfer of knowledge and information about developments in psychology.

Categories of articles to be published and manuscripts to be welcomed are:

Review articles

Manuscripts should be limited to a maximum of 8000 words. Authors planning contributions that exceed this maximum must contact the editor prior to submitting their manuscript.

Original reports of empirical research

Manuscripts should be limited to a maximum of 5000 words. Authors planning contributions that exceed this maximum must contact the editor prior to submitting their manuscript.

Thematic issues

Authors with plans for planning a thematic issue are encouraged to contact the editor in an early stage. Consultation will be necessary about the number of manuscripts, number of words per manuscript, review procedure, covering of the field, etc.

Developments in the field (short)

Manuscripts should be limited to a maximum of 1000 words. Authors planning contributions that exceed this maximum must contact the editor prior to submitting their manuscript.

Book review essays (short)

Manuscripts with a maximum of 1000 words need no preliminary contact with the editor. Authors planning larger contributions must contact the editor.

Letters to the editor

Manuscripts should be limited to a maximum of 500 words. Authors planning contributions that exceed this maximum must contact the editor prior to submitting their manuscript.

Technical notes

Manuscripts should be limited to a maximum of 2000 words. Authors planning contributions that exceed this maximum must contact the editor prior to submitting their manuscript. Authors reporting (in English) on, e.g. validation of tests and other instruments in the Dutch language or in the Netherlands are encouraged to report in *The Netherlands Journal of Psychology*. The editors want to inform non-Dutch researchers of developments and of the use of instruments in the Dutch language.

Editor

René van Hezewijk
Open University of the Netherlands

Associate editors

Frederik Anseel *Ghent University*
Maaike Cima *Tilburg University*
Paul van Geert *University of Groningen*
Karljin Massar *Maastricht University*
Annemarie Zand Scholten *University of Amsterdam*

Editorial board

O. van den Berg *University of Leuven*
A. Bos *Open University of the Netherlands*
N. Elleemers *Leiden University*
A. Fischer *University of Amsterdam*
E. de Haan *University of Amsterdam*
J. van Heerden *Maastricht University*
M. van den Hout *Utrecht University*
J. Jolles *Maastricht University*
W. Koops *Utrecht University*
W. Schaufeli *Utrecht University*
R. Schreuder *Radboud University Nijmegen*
H.J. Stam *University of Calgary*
D. Wigboldus *Radboud University of Nijmegen*

Editor's address

Professor René van Hezewijk
Faculty of Psychology, Open University of the Netherlands, PO Box 2960,
6401 DL Heerlen, the Netherlands
tel + 31 45 576 23 99
All correspondence by e-mail: rene.vanhezewijk@ou.nl

Publisher: Nederlands Instituut van Psychologen,
PO Box 2085, 3500 GB Utrecht, the Netherlands

Subscription rates

Personal rate: € 125.–
Institutional rate: € 226.–
Student rate: € 62.50
All prices are per calendar year and include value added tax (VAT)
Price per issue: € 31.95 (incl. VAT)

Subscription administration

Performis Media, PO Box 2396, 5202 CJ 's Hertogenbosch, the Netherlands, tel:
+ 31 73 689 58 89. For information and orders, please consult www.performis.nl

Change of address

Please notify any changes in addressee and/or address via
www.performis.nl.

Payment

Please use the payment/accept giro form if possible as this simplifies the administrative process.

Advertisements

Performis Media, PO Box 2396, 5202 CJ 's Hertogenbosch,
the Netherlands, tel: + 31 73 689 58 89.

The *Netherlands Journal of Psychology* is published four times a year.

Contents

VOLUME 67, NUMBER 2, NOVEMBER 2012

- Evaluation of an online HIV-prevention intervention to promote HIV testing among men who have sex with men:
a randomised controlled trial
Jochen Mikolajczak, Gerard J.P. Van Breukelen, Gerjo Kok, and Harm J. Hospers 21
-
- Letter to the editor
Psychological care in cancer patients and their caregivers: Who gets help, why, when, and how?
Sanne Krul, Marjet Docter, Christine Brouwer-Dudok de Wit, and Irma M. Verdonck-de Leeuw 36

Evaluation of an online HIV-prevention intervention to promote HIV testing among men who have sex with men: a randomised controlled trial

Background. This paper describes the effect and process evaluation of a systematically developed online HIV-prevention intervention aimed at promoting HIV testing among men who have sex with men (MSM) in the Netherlands. The intervention was named Queermasters.

Methods. An online randomised controlled trial (RCT) in which, for one month, visitors of the website queermasters.nl ($N = 5030$) were randomly assigned to either the newly developed intervention (experimental group) or an existing online HIV test promotion intervention (control group). Prior to randomisation, participants completed a pretest in which demographics and determinants of taking an HIV test, including their motivation to take an HIV test within the next three months, were measured. Directly after participation in either of the two interventions, participants' motivation to take a test within the next three months was again asked. Three months later, participants received an invitation by e-mail to participate in a posttest in which HIV-testing behaviour was measured.

Results. Mixed linear regression analysis, including available data of all participants who finished the pretest and were randomised ($N = 1704$) and adjusting for prognostic variables, suggested that the newly developed intervention was significantly better at motivating participants to take an HIV test (mean difference on a seven-point scale = .78, $P < .001$; 95% CI .97 to .59, intention to treat analysis). Directly after participating in one of the two interventions, intention to take an HIV test was significantly higher (5.27 vs. 4.41) among completers in the experimental group ($N = 638$) compared with completers in the control group ($N = 787$). During the pretest, no difference was observed between the experimental group ($N = 870$) and the control group ($N = 834$) on this variable (3.98 vs. 3.92). A difference at the level of testing behaviour three months later, to be expected from the previous finding concerning participants' intention to take a test, was however not observed. The newly developed intervention was positively judged by its participants.

Conclusions. Queermasters is an effective online intervention to motivate MSM to take an HIV test. In the absence of an effect at the level of testing behaviour, however, further adaptation of the intervention is needed to reduce the gap between intention and behaviour. Implications of the findings are discussed and suggestions for adaptations of the intervention are presented.

Where: Netherlands Journal of Psychology, Volume 67, 21-35

Received 27 March 2012; Accepted 31 July 2012

Keywords: Randomized Controlled Trial; Intervention study; Internet; HIV prevention; Men who have sex with men (MSM)

Authors: Jochen Mikolajczak*, Gerard JP Van Breukelen*, Gerjo Kok*, and Harm J. Hospers**

* Department of Work and Social Psychology, Maastricht University, Maastricht, the Netherlands,
** University College Maastricht, Maastricht University, Maastricht, the Netherlands

Correspondence to:
Jochen Mikolajczak,
National Institute for Public Health and the Environment, Centre for Prevention and Health Services Research, PO Box 1, 37230 BA Bilthoven, the Netherlands), e-mail: jochen.mikolajczak@rivm.nl

Introduction

This paper describes the evaluation of the effects of a health promotion program that was developed to motivate Dutch Men who have Sex with Men (MSM) to take an HIV test. A new and systematically developed online intervention was compared with an existing online intervention in an RCT design. The development of the new intervention was guided by the Intervention Mapping (IM) protocol (Bartholomew, Parcel, Kok, Gottlieb, & Fernández, 2011). This ensured that, to a maximal degree, program development was systematically planned on the basis of available theory and evidence (Kok Schaalma, Ruiters, Van Empelen, & Brug, 2004; Schaalma & Kok, 2009). Intervention mapping guides program planners to map the path of intervention development from recognising a need or problem to testing solutions. It describes the intervention development process in six phases: (1) assessing the problem and community capacities, (2) specifying program objectives, (3) selecting theory-based intervention methods and practical applications, (4) designing and organising the program, (5) planning, adoption and implementation and (6) developing an evaluation plan (see Kok, Harterink, Vriens, De Zwart, & Hospers, 2006; Wolfers, Van den Hoek, Brug, & De Zwart, 2007; http://en.wikipedia.org/wiki/Intervention_mapping). The planned development of Queermasters using intervention mapping is described in Mikolajczak, Kok, and Hospers (2008). The newly developed intervention was named Queermasters. To motivate MSM to take an HIV test, Queermasters introduced the concept of regular Sexual Health Checkups and focused primarily on their advantages, attempting to influence the perceived social norm towards taking such checkups among MSM. Conform the current Dutch policy on HIV and STI testing, a Sexual Health Checkup includes a test for the so-called 'Big Five': HIV, syphilis, gonorrhoea, hepatitis B and chlamydia. An existing online intervention that focused on both risk information and risk communication to motivate MSM to take an HIV and/or an STI test, served as the control condition in the RCT. Contrary to the control intervention, Queermasters deliberately avoided the use of risk information and risk communication as a method to motivate MSM to get tested. This decision was taken on the basis of findings in our previous studies (Mikolajczak, Van Kesteren, Hospers, Kok, 2004; Mikolajczak, Hospers, & Kok, 2006; Mikolajczak et al., 2008) which suggested that increasing perceived risk for HIV infection was unlikely to motivate Dutch MSM to take an HIV test since it might lead to an increase in the level of fear that is experienced. This might consequently lead to a defensive reaction in which one attempts to reduce unpleasant feelings as quickly as possible – for example by denying

the threat or avoiding information about past sexual risk behaviour – in order to achieve a feeling of safety (Ruiters, Verplanken, De Cremer, & Kok, 2004). Further support for the decision not to use risk communication as a method to motivate MSM to take an HIV test in Queermasters was provided by the finding that perceived risk for HIV infection was not associated with increased HIV testing (Lauby, Bond, Erğolu, & Batson, 2006). Adequate knowledge about the Dutch HIV-testing policy, HIV-testing procedures, and specific aspects of taking an HIV test such as the costs involved, appeared to be limited among MSM. Our earlier studies also showed that HIV testing was neither encouraged nor reinforced by respondents' social environment, and was hardly ever talked about with significant others (i.e. good friends). More details on the development of Queermasters are reported elsewhere (Mikolajczak, Kok & Hospers, 2008).

The Netherlands' current HIV-testing policy (Gezondheidsraad, 1999; Tweede Kamer, 2003), which focuses on the promotion of HIV testing among individuals at high(er) risk for HIV infection, prompted the development of effective health promotion programs that would focus specifically at the promotion of HIV testing among MSM. Moreover, the need for such a program was, and still is, also fostered by the observation that a large proportion of MSM in the Netherlands are still unaware of their HIV status. The most recent figures from a large-scale online monitoring study among MSM in the Netherlands show that 66% of the respondents have ever taken an HIV test (Hospers, Dörfler, & Zuilhof, 2008). Although this figure is slightly higher compared with the figure that was found one year before (63%) (Hospers, Dörfler, Zuilhof, & Nijman, 2007), and is substantially higher than the figure that was found in the first wave of this study in 2000 (47%) (Hogeweg & Hospers, 2000), it remains relatively low when compared with the figures that are reported in other Western countries. In Australia, for example, behavioural studies among MSM that have been conducted over the past years consistently report HIV-testing rates of about 85% and more among MSM, according to the NCHSR (2005).

As a consequence of the relatively low HIV-testing rates among MSM in the Netherlands, it is likely that a substantial number of MSM are unaware of their HIV infection. Consequently, these men miss out on the benefits that are related to treatment of HIV infection with HAART nowadays. In addition, many of them may also continue to place their sex partners at risk for HIV infection through sexual risk behaviour. It is thus expected that the beneficial effects of motivating (more) MSM in the Netherlands to take an HIV test are twofold.

First of all, the health status of individual men who find out that they are infected with the virus can be monitored and treatment with HAART can be initiated at an adequate moment in time. As a result, the effectiveness of treatment with HAART is optimised. It should be noted that although HAART can have negative side effects, the overall advantages of HAART and its positive effects on quality of life and life expectancy of HIV-infected individuals are currently widely acknowledged (Ives, Gazzard, & Easterbrook, 2001; Matic, Lazarus, & Donoghoe, 2006; Saunders & Burgoyne, 2000). Second, it can be expected that men who find out that they are infected with the virus will significantly reduce their level of sexual risk behaviour (Marks, Crepaz, Senterfitt, & Janssen, 2005; Weinhardt, Carey, Johnson, & Bickham, 1999), which in turn will reduce the spread of the virus in the MSM population in the Netherlands. It is also noteworthy that the available evidence does not support the idea that finding out about being HIV negative leads to a significant increase in sexual risk behaviour among MSM (Weinhardt et al., 1999).

We hypothesised 1) that exposure to the newly developed intervention would lead to a significant increase in participants' intention to take an HIV/STI test (i.e., a Sexual Health Checkup), compared with exposure to the control intervention; and 2) that, compared with the control condition, significantly more participants in the experimental condition would have taken a Sexual Health Checkup at the moment of follow-up.

Finding out whether or not an intervention is effective in achieving its goals and objectives is an important aspect of program development (Bartholomew et al., 2011). Therefore, both a process and effect evaluation of Queermasters were conducted. Evaluation of the effects of our newly developed program was achieved by comparing it with an existing online intervention on a number of relevant outcome variables. The process evaluation included a comparison of participants' overall rating of the intervention in which they participated (either the experimental or the control condition), and a set of evaluative questions concerning the intervention in which they participated.

Methods

Participants

Participants for our intervention study were recruited both online and offline. Online recruitment was achieved by placing banners on several large and popular Dutch MSM websites, by placing a click-through button on the home page of the most popular Dutch MSM chat website (www.chatboy.nl), and by placing a chatter's profile in the Chatboy chatbox

inviting visitors to participate. Offline recruitment was done by advertisements in the popular Dutch MSM press. The intervention study described in this paper was approved by the Ethics Committee of the Faculty of Psychology at Maastricht University.

Procedure

During the 28 days online period of our intervention study, from 1 November until 28 November 2006, a total of 5030 men started our program by completing the first question in the questionnaire. Of these, a number were excluded for further statistical analyses because they did not meet the inclusion criteria for the intervention study ($N = 1018$). Inclusion criteria for the intervention study were: having had casual sex partners in the past six months (827 had not), not being HIV positive (191 were HIV positive), and living in the Netherlands (all). Participants were also excluded for further statistical analyses if they had not completed all the questions on demographics ($N = 1003$), or lived in the city of Nijmegen ($N = 123$). For the purpose of another evaluation study, participants living in the city of Nijmegen were not randomly assigned to one of the two intervention conditions, but always assigned to the experimental intervention. After deleting these records, the dataset that was used for statistical analyses to evaluate the intervention effects contained 2886 unique records. Of these, 1704 men (59%) finished the questionnaire (that preceded randomisation to the experimental and control group), which included questions on demographics, a request for a valid e-mail address and a pretest measurement of Theory of Planned Behaviour variables (TPB) (Ajzen, 1991) including their intention to take an HIV test within the next three months. After finishing this part of the program, these respondents were randomly assigned to either the experimental intervention condition or the control intervention condition by means of a programmed randomisation procedure. Of the respondents who were randomly assigned to one of the intervention conditions, 1425 men (84%) completed the intervention part including an immediate posttest measurement of their intention to take an HIV/STI test within the next three months, and thereby finished the complete pretest of our intervention study.

Three months after finishing the first session of Queermasters, all 1425 men received an e-mail, in which they were invited to participate in a follow-up session. In total, 612 men reacted to our e-mail invitation and started the follow-up session of Queermasters, which included the question whether or not they had taken an HIV and/or an STI test during the past three months. Of the men who started the follow-up session of Queermasters, 529 men (86%) completed it. Details on the flow of the number of participants in our intervention study can be found in [Figure 1](#).

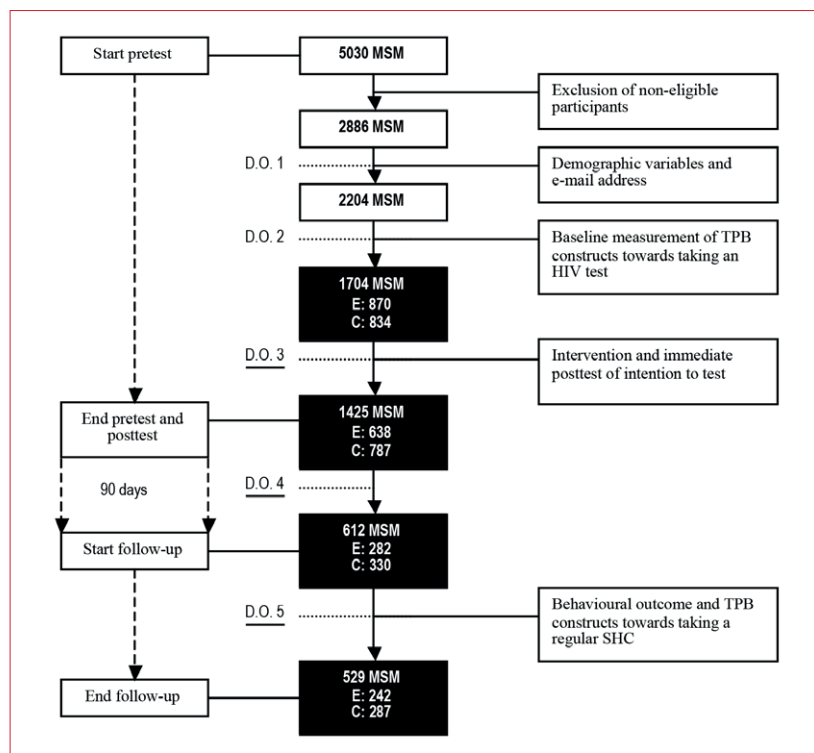


Figure 1 Flowchart of Queermasters: participants, key activities conducted and drop-out analyses (D.O.)

Note: black boxes concern the number of participants in the study after randomisation to condition

Intervention

A new online intervention, Queermasters, was compared with an existing online intervention. The existing online intervention focused on both risk information and risk communication to motivate MSM to take an HIV/STI test. Unfortunately, that intervention is not systematically described, but seems to apply theoretical methods (or behaviour change techniques) such as consciousness raising, personalising risk, scenario-based risk information, and framing. The planned development of Queermasters using intervention mapping is described elsewhere (Mikolajczak et al., 2008). Queermasters deliberately avoided the use of risk information and risk communication, and introduced the concept of regular Sexual Health Checkups, focusing primarily on their advantages and attempting to influence the perceived social norm, applying methods such as tailoring, arguments, information about others' approval, and modelling.

Materials

For the purpose of our online RCT, a Rich Internet Application (RIA), which can be considered a website application with the features and functionalities of a traditional desktop application, was developed and hosted on www.queermasters.nl.

The back-end of our RIA consisted of an MYSQL database; the front-end for the users of our RIA was a Flash application.

The program that comprised the pretest in our intervention study consisted of two distinct parts. The first part contained an interactive questionnaire which asked for demographic information, a valid e-mail address and measurement of the different constructs of the Theory of Planned Behaviour (TPB), of which some were used as a pretest measure of outcome variables. Demographic variables of interest were age, educational level (recoded to 0 = lower; 1 = higher), cultural background (recoded to 1 = Dutch; 2 = Dutch + other; 3 = Non Dutch), sexual attraction (recoded to 0 = bisexual; 1 = homosexual), HIV-testing history (0 = never tested; 1 = tested longer than nine months ago; 2 = tested within the past nine months), STI testing in the past nine months (0 = no; 1 = yes), steady partner status (0 = no; 1 = yes) and sexual risk behaviour with casual partners in the last six months preceding the questionnaire (recoded to 0 = no risk behaviour; 1 = risk behaviour). In addition, participants were asked to provide the first two numbers of their postal code and the name of the province in which they currently resided. The first question allowed us to calculate whether participants lived in an urban or a rural part (0 = rural; 1 = urban) of the Netherlands, by applying the official criteria provided by the Dutch Central Bureau of Statistics (CBS). The second question allowed us to make a distinction between participants living in the 'Randstad' and participants living outside this urban agglomeration in the western part of the Netherlands (0 = other; 1 = Randstad). This distinction may be relevant in the context of promoting HIV testing, given there are more testing facilities in the 'Randstad' than in the rest of the Netherlands. No statistically significant differences between the experimental (EXP) and the control (CTRL) condition were found on any of the demographic characteristics that were measured, as expected given the randomised assignment of participants to condition. An overview of the demographic features of MSM respondents at various points in the study is provided in Table 1.

After finishing the questions on demographic variables of interest, participants were asked to provide us with a valid e-mail address. For the purpose of our online RCT, this was necessary since participants were offered the option to receive extra information on certain topics later on in our program, for example during their intervention. In addition, a valid e-mail address was needed for us to be able to invite respondents to participate in a three-month follow-up session of Queermasters.

Table 1 Overview of demographics among MSM participants at three different points in the study

Demographics	Full sample (N = 2886)		At randomisation (N = 1704)		At 3-months follow-up (N = 529)					
			EXP	CTRL	EXP	CTRL				
Age (mean)	36		36	36	38	38				
Educational level ^a										
Lower	1345	(47%)	403	(47%)	388	(47%)	99	(41%)	138	(48%)
Higher	1525	(53%)	457	(53%)	443	(53%)	141	(59%)	148	(52%)
Cultural background ^b										
Dutch	2485	(86%)	740	(85%)	728	(87%)	208	(86%)	261	(91%)
Dutch and other	179	(6%)	57	(7%)	57	(7%)	12	(5%)	16	(6%)
Non-Dutch	218	(8%)	72	(8%)	49	(6%)	22	(9%)	10	(3%)
Randstad										
Randstad	1437	(50%)	459	(53%)	410	(49%)	135	(56%)	135	(47%)
Other	1449	(50%)	411	(47%)	424	(51%)	107	(44%)	152	(53%)
Living area										
Rural	1160	(40%)	336	(39%)	342	(41%)	101	(42%)	110	(38%)
Urban	1726	(60%)	534	(61%)	492	(59%)	141	(58%)	177	(62%)
Sexual orientation										
Bisexual	519	(18%)	116	(13%)	108	(13%)	29	(12%)	23	(8%)
Homosexual	2367	(82%)	754	(87%)	726	(87%)	213	(88%)	264	(92%)
Steady partner										
No	1912	(66%)	564	(65%)	534	(64%)	157	(65%)	181	(63%)
Yes	974	(34%)	306	(35%)	300	(36%)	85	(35%)	106	(37%)
Risk casual partners										
No	2038	(71%)	593	(68%)	585	(70%)	162	(67%)	195	(68%)
Yes	848	(29%)	277	(32%)	249	(30%)	80	(33%)	92	(32%)
HIV testing										
Never tested	1232	(43%)	334	(39%)	332	(40%)	98	(40%)	112	(39%)
>9 months ago	791	(27%)	254	(29%)	246	(29%)	65	(27%)	88	(31%)
<9 months ago	863	(30%)	282	(32%)	256	(31%)	79	(33%)	87	(30%)
STI testing										
No	1968	(68%)	577	(66%)	563	(67%)	156	(65%)	195	(68%)
Yes	918	(32%)	293	(34%)	271	(33%)	86	(35%)	92	(32%)

^a N = 2870 in full sample due to missing data; ^b N = 2882 in full sample due to missing data

After providing us with a valid e-mail address, participants were asked to fill in the questions on TPB constructs. Most of these constructs were measured using multiple items, which were subjected to reliability analysis to allow item summation and calculation of a mean score for each of the constructs (range 1 – 7), given a sufficient reliability coefficient. In the context of the present study, the TPB constructs were operationalised as follows:

Intention to take an HIV test within the next three months was measured with two items. For example: ‘I intend to take an HIV test within the next three months’, measured on a seven-point scale (very definitely not – very definitely so), correlation: .89.

Attitude towards taking an HIV test within the next three months was measured with four items. For

example: ‘I consider taking an HIV test within the next three months to be ...’, measured on a seven-point scale (very unwise – very wise), Cronbach’s alpha: .84.

Subjective social norm towards taking an HIV test within the next three months was measured with two items. For example: ‘My best friends think that I should take an HIV test within the next three months’, measured on a seven-point scale (very definitely not – very definitely so), correlation: .77.

Self-efficacy towards taking an HIV test in the next three months was measured with eight items. For example: ‘I consider making an appointment to take an HIV test at a testing location to be ...’, measured on a seven-point scale (very difficult – very easy), Cronbach’s alpha: 0.84.

After completing the set of questions on the TPB constructs, participants were randomly assigned to one of the two intervention conditions (0 = experimental, 1 = control), which can be considered the second part of the program that comprised the pretest phase of our intervention study. Immediately after finishing their intervention, participants' intention to take an HIV and/or an STI test (referred to as a Sexual Health Checkup in the experimental condition) was measured (immediate posttest). Our hypothesis was that after exposure to the intervention material, participants' intention to test would be significantly higher among participants in the experimental condition compared with participants in the control condition.

Ninety days after participants had finished Queermasters, they received an e-mail which invited them to participate in a follow-up session. Variables of interest that were measured during follow-up were whether or not participants had taken an HIV test and/or an STI test (referred to as a Sexual Health Checkup throughout the follow-up session of Queermasters) in the past three months, TPB constructs concerning taking a Sexual Health Checkup at a yearly basis (instead of taking an HIV test in the next three months as measured during the pretest), and a set of questions for the process evaluation of Queermasters. Most of the TPB constructs were measured using multiple items, which were subjected to reliability analysis to allow item summation and calculation of a mean score for each of the constructs (range 1 – 7), given a sufficient reliability coefficient (attitude Cronbach's alpha: .81; subjective social norm Cronbach's alpha: .77; self-efficacy correlation: .75).

After completing this set of TPB questions, participants in both intervention conditions were also asked to indicate on a seven-point scale (totally disagree - totally agree) whether they: 'had enjoyed participating in Queermasters', 'considered the content of Queermasters to be useful', 'Queermasters gave them a better perspective on taking an HIV and an STI test' and 'would advise others to participate in Queermasters'.

Statistical analysis

Differences were considered statistically significant at a P value $< .01$, two-tailed in order to adjust for multiple outcome testing (Bonferroni alpha: .013). Because of the complexity of the data analyses, especially the corrections for attrition, we will describe the various analyses in the Results section.

Results

Dropout analyses

As can be seen in [Figure 1](#), the number of respondents decreased during the flow of our

online intervention study. Therefore, we checked whether demographic and other background variables were related to dropout at any point during the study, using logistic regression with dropout (1 = yes; 0 = no) as outcome and treatment condition and demographics as predictors. In each dropout analysis, non-significant predictors were removed, using $P > .01$ as the criterion for removal, to obtain a parsimonious final logistic regression model. Collinearity between predictors was checked by computing the variance inflation factors (VIF) (Fields, 2005). No VIFs > 3 were found, ruling out collinearity between predictors. The results of the different dropout analyses can be found in [Table 2](#).

As can be seen in [Table 2](#), dropout analysis 1 shows that compared with younger men and with homosexual men, both older men and bisexual men had a significantly higher chance to drop out of our intervention study when they were asked for a valid e-mail address. The outcome of dropout analysis 2 shows that of the men who provided us with a valid e-mail address, younger men had a significantly higher chance to drop out of our intervention study compared with older men when TPB questions were asked. Also, bisexual men had a significantly higher chance to drop out compared with homosexual men at this stage. Both dropout analysis 1 and 2 concerned participant dropout before random assignment to one of the two intervention conditions. Therefore, they are relevant to the issue of generalisability of our results, to be discussed in the last section of our paper.

Dropout analysis 3 shows that men who were assigned to the experimental condition had a significantly higher chance to drop out during the intervention, compared with men who were assigned to the control condition. Dropout analysis 4 shows that of the men who were invited to participate in the follow-up session of Queermasters, older men had a significantly lower chance to drop out. Finally, dropout analysis 5 shows that of the men who started the follow-up session of Queermasters, homosexual men had a significantly lower chance to drop out of the follow-up session, compared with bisexual men. Dropout analyses 3, 4 and 5 concerned participant dropout after the random assignment to one of the two intervention conditions, and are thus relevant to the question of internal validity and selection bias. This type of dropout was taken into account in all further reported analyses by entering the significant variables from dropout analyses 3, 4 and 5 into the statistical models as covariates and by intention to treat outcome analyses including all available data of all participants randomised to either treatment.

Table 2 Overview of final logistic regression models, predicting participant dropout (1=yes; 0=no) at any point in the study

Dropout analysis	Two-tailed Predictors	B	95% CI SE	Exp(B) Significance	Exp(B)	Lower	Upper
Before randomisation							
D.O. 1 (N=2866)	Age	.013	.004	.002	1.01	1.00	1.02
	Sexual orientation	-.549	.108	<.001	.577	.467	.713
	Constant	-1.02	.177	<.001	.362		
D.O. 2 (N=2204)	Age	-.024	.005	<.001	.976	.967	.986
	Sexual orientation	-.711	.128	<.001	.491	.382	.631
	Constant	.335	.203	.10	1.39		
After randomisation							
D.O. 3 (N=1704)	Intervention condition	-1.80	.169	<.001	.167	.120	.232
	Constant	-.178	.292	.54	.837		
D.O. 4 (N=1425)	Age	-.025	.005	<.001	.976	.967	.985
	Constant	1.18	.187	<.001	3.27		
D.O. 5 (N=612)	Sexual orientation	-1.12	.306	<.001	.325	.178	.592
	Constant	-1.66	.504	.001	.190		

Predictors included in dropout analysis (D.O.) 1 and 2: age, educational level (0 = lower; 1 = higher), sexual orientation (0 = bisexual; 1 = homosexual), STI test (0 = no; 1 = yes), steady partner (0 = no; 1 = yes), risk casual partners (0 = no; 1 = yes), HIV testing (0 = never tested; 1 = tested more than 9 months ago; 2 = tested within past 9 months), living area (0 = rural; 1 = urban), Randstad (0 = other; 1 = Randstad), cultural background (1 = Dutch; 2 = Dutch and other; 3 = non-Dutch); Dropout analyses 3, 4 and 5 also included intervention condition (0 = experimental; 1 = control), pretest measures of intention to take an HIV test, attitude and self-efficacy towards taking an HIV test; Actual *N* about 1% less than indicated due to missing values on predictors; SE = standard error

Effect of the intervention on participants' intention to take an HIV test at immediate posttest

We hypothesised that exposure to the newly developed intervention would lead to a significant increase in participants' intention to take an HIV/STI test (i.e., a Sexual Health Checkup), compared with exposure to the control intervention. To test our hypothesis, a repeated measures analysis with mixed linear regression was conducted. Available data of all 1704 randomised participants were used in this method of analysis. In contrast with repeated measures ANOVA or ANCOVA, this method allows the inclusion of all participants with a missing value on either time point (pretest or

immediate posttest) without requiring imputation. This method of analysis is valid under so-called missing at random (MAR) missingness, whereas both ANOVA and ANCOVA require the more restrictive missing at completely random (MCAR) assumptions (Schafer & Graham, 2002; Verbeke & Molenberghs, 2000). Our basic mixed model assumed that participants' intention to take a Sexual Health Checkup depended on time (0 = pretest; 1 = immediate posttest), intervention condition (0 = experimental; 1 = control), and time by intervention condition interaction (assuming a so-called unstructured covariance matrix for the repeated measures; for further details of this mixed model compared with standard ANOVA and ANCOVA see Van Breukelen, 2006). All background variables that were predictive of dropout after random assignment to intervention condition were included as covariates in our final mixed model as predictors of participants' intention to test. Other covariates were removed from the model if non-significant (see Table 2 note for an overview), using $P > .01$ as the criterion for removal, to obtain a parsimonious final mixed model. Mean scores of participants' intention to test are displayed in Table 3 and are also shown graphically in Figure 2.

Table 3 Participants' mean intention score on pretest (time = 0) and on immediate posttest (time = 1), per intervention condition (0 = experimental, 1 = control)

Intervention condition	Pretest (N)	Immediate posttest (N)
Experimental	3.98 (870)	5.27 (638)
Control	3.92 (834)	4.41 (787)
Total	3.95 (1704)	4.79 (1425)

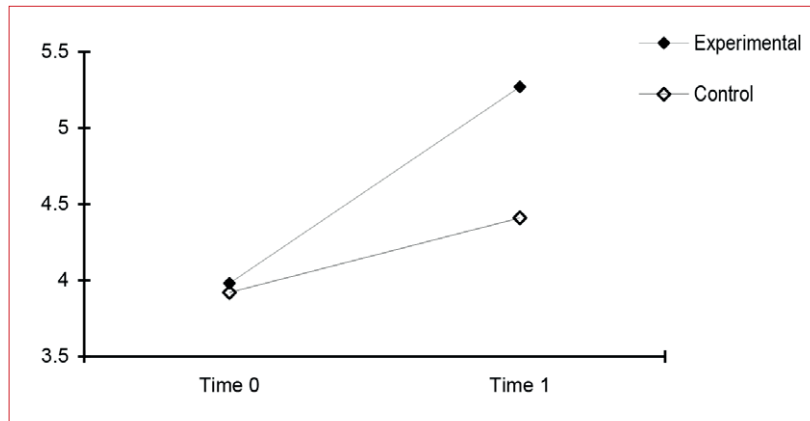


Figure 2 Graphical display of participants' mean intention score (Y axis) on pretest (Time = 0) and on immediate posttest (Time = 1), per intervention condition (0 = experimental, 1 = control)

Table 4 summarises the final mixed regression model for participants' intention to test. Given the coding of time (0 = pretest; 1 = immediate posttest), the main effect of intervention condition represents the difference in participants' intention at pretest, which is expected to be absent as a result of randomised treatment assignment. Likewise, given the coding of intervention condition (0 = experimental; 1 = control), the main effect of time represents the change of intention in the experimental group from pretest to immediate posttest. The time by treatment interaction represents the difference between the two groups with respect to change from baseline, which in turn equals their difference at immediate posttest if there is no baseline group difference. This interaction effect is highly significant ($P < .001$) and substantial, that is: .78 points on the seven-point scale for intention (1 = very low intention; 7 = very high intention) in favour of the experimental group. Additionally, participants' intention at immediate posttest is lower for older participants, and higher for homosexual men compared with bisexual men.

Effects of the intervention on testing behaviour at follow-up

Motivating participants to take an HIV test was one aspect of the evaluation of the effects of our program. Whether or not participants actually got tested after completing their intervention, in a time frame of three months, was another important indicator of the effectiveness of our program. Theory predicts that high intentions towards taking a test increase the chances of actually taking a test. As such, we hypothesised that compared with the control condition, significantly more participants in the experimental condition would have taken a Sexual Health Checkup at the moment of follow-up. In view of the substantial dropout between randomisation and follow-up, a mixed logistic regression of testing behaviour, analogously to the mixed linear regression of participants' intention to test, is the optimal method of analysis (Van Breukelen, 2006). However, behaviour was measured with respect to the last three months at follow-up versus the last nine months at pretest, making pretest and follow-up less comparable. Therefore, we ran two effect analyses in order to check agreement between the two with respect to the resulting effect of intervention condition on testing behaviour:

1. A logistic regression with testing behaviour (taking a Sexual Health Checkup) at follow-up as outcome, and intervention condition (0 = experimental, 1 = control), intention and HIV-testing behaviour at pretest, and background variables as predictors ($N = 529$ complete cases). As background variables we included all variables that predicted dropout *after randomisation* (Table 2). In view of the severe dropout from pretest ($N = 1704$) to follow-up ($N = 529$), we also checked whether any of the background variables were correlated with intervention condition (0 = experimental; 1 = control) in the final sample of 529 complete

Table 4 Final mixed linear regression model of participants' intention to test ($N = 1704$)

Predictor	Estimate	SE	T	Two-tailed Significance	95% CI Lower	Upper
Intervention condition	-.05	.10	-.44	.66	-.25	.16
Time	1.27	.07	17.95	<.001	1.13	1.41
Intervention condition x Time	-.78	.10	-8.06	<.001	-.97	-.59
Age (in years)	-.02	.00	-4.1	<.001	-.02	-.01
Sexual orientation	.35	.13	2.63	.008	.09	.61
Intercept	4.26	.20	21.73	<.001	3.88	4.65

SE = standard error; Intervention condition: 0 = experimental, 1 = control; Time: 0 = pretest, 1 = posttest

cases. From this analysis, it appeared that men living in the ‘Randstad’ (0 = other; 1 = Randstad) had a significantly lower chance to be represented in the control condition, compared with men not living in the ‘Randstad’ ($B = -.622$; $Exp(B) = .537$; $P = .003$, also see Table 1). This variable was therefore included as covariate in the effect analyses. All background variables that were predictive of dropout after random assignment to intervention condition, and background variables that were predictive of intervention condition in the final sample of 529 cases were kept in the final logistic regression model. Other background variables were removed if not significant, using $P > .01$ as the criterion for removal, to obtain a parsimonious final regression model.

2. A mixed logistic regression using MLwiN, with testing behaviour as outcome, and time (0 = pretest, 1 = follow-up), intervention condition (0 = experimental, 1 = control), time by intervention condition and background variables as predictors ($N = 1704$ participants, using all available data).

Table 5 shows the results for the first method of analysis. The results of the second method were similar to the results of the first, and are therefore not reported here.

Results from the logistic regression analysis to test for a difference in behavioural outcome between the experimental condition and the control condition show that there is no significant difference between the two intervention conditions. As such, our program did not have the hypothesised effect on behaviour at three-month follow-up. This can also be seen in the behavioural outcome data that are presented in Table 6. The analysis presented in Table 5 does show that participants with a more positive intention towards taking an HIV test, measured before exposure to any intervention material, have a significantly higher chance to have taken a Sexual Health Checkup at three-month follow-up. Also, participants who indicated that they had ever taken an HIV test (recently) have a significantly higher chance to have taken a Sexual Health Checkup at three-month follow-up. Table 6 shows the distribution of testing behaviour at three-month follow-up per intervention condition, per level of HIV-testing behaviour at pretest.

Table 5 Logistic regression of taking a Sexual Health Checkup [HIV and/or STI test] at three-month follow-up, with predictors: intervention condition [0=experimental; 1 = control], HIV testing and intention to test at pretest, and background variables related to dropout ($N = 529$)

Predictor	B	SE	Two-tailed Significance	95% CI for Exp(B)		
				Exp(B)	Lower	Upper
Intervention condition	0.341	.236	.15	1.407	.885	2.23
Age	-0.002	.011	.83	.998	.977	1.02
Sexual orientation	0.104	.485	.83	1.110	.430	2.87
Randstad	0.113	.233	.63	1.120	.710	1.77
HIV testing (pretest)	0.629	.181	.001	1.876	1.32	2.67
Intention (pretest)	0.260	.071	<.001	1.297	1.13	1.50
Constant	-3.45	.696	<.001	.032		

SE = standard error

Table 6 Distribution of taking a Sexual Health Checkup (SHC) at three-month follow-up, by intervention condition [0 = experimental; 1 = control], and by HIV-testing behaviour at pretest

Intervention condition	SHC at follow-up		HIV test at pretest	
			Yes	No
Experimental	Yes	47 [20%]	30 [38%]	17 [11%]
	No	195 [80%]	49 [62%]	146 [89%]
	Total	242	79	163
Control	Yes	67 [23%]	40 [46%]	27 [14%]
	No	220 [77%]	47 [54%]	173 [86%]
	Total	287	87	200
Grand total		529	166	363

Table 7 Participants' mean score on attitude, social norm, self-efficacy and intention to take a regular Sexual Health Checkup, per intervention condition ($N_{max} = 527$)

Intervention condition	Outcome variable			
	Attitude	Self-efficacy	Social norm	Intention
Experimental	5.37	5.13	4.83	4.68
Control	5.12	5.12	4.85	4.37
Total	5.23	5.12	4.84	4.51

Lower N (527) than expected (529) for attitude, self-efficacy and intention because HIV-positive men at follow-up received a different set of questions; Lower N (460) than expected for social norm due to missing data

Effects of the intervention on determinants of taking a regular Sexual Health Checkup at follow-up

A final aspect of the evaluation of the effects of Queermasters concerns its effects on participants' attitude, social norm, self-efficacy and intention to take a Sexual Health Checkup on a regular basis (at least once every year). Table 7 summarises participants' mean score on all four outcome variables of interest here.

Evaluation of the effects of Queermasters on participants' attitude, perceived social norm, self-efficacy and intention to take a Sexual Health Checkup on a regular basis (at least once every year) was also hampered by the substantial dropout between randomisation ($N = 1704$) and follow-up ($N = 529$) and by the difference between follow-up and pretest with respect to the time scale for taking a checkup (i.e. the next year at follow-up versus the next three months at pretest). In view of this, we ran two effect analyses to check agreement between the two with respect to the outcome variables of interest:

1. Linear regression, with attitude, social norm, self-efficacy or intention to take a Sexual Health Checkup on a regular basis (at least once per year) as outcome, and intervention condition (0 = experimental, 1 = control), attitude, social norm, self-efficacy or intention at pretest, and background variables as predictors ($N = 529$). As background variables we included all variables that predicted dropout after randomisation (Table 2). In each regression analysis, non-significant predictors were removed to obtain a parsimonious model. Collinearity between predictors was checked by computing the VIF (Field, 2005). No VIFs > 3 were found, ruling out collinearity between predictors.
2. A repeated measures analysis with mixed linear regression ($N = 1704$, using all available data), to check agreement with the results obtained in the above-described complete cases analysis. For the

mixed regression analyses, attitude, social norm, self-efficacy and intention to take an HIV test at pretest and at follow-up were both treated as repeated measures, following the same model as for intention at immediate posttest in Table 4.

Table 8 shows the results for the first method of analysis. The results obtained with the mixed linear regression procedure were similar to these results and are therefore not reported here.

The results presented in Table 8 show that at an α -level of .01 two-tailed, none of the four determinants differ significantly between the two intervention conditions. However, with respect to participants' attitude and intention to take a regular Sexual Health Checkup, the results presented in Table 8 do suggest a trend towards a significant difference between the two intervention conditions in favour of Queermasters (0 = experimental, 1 = control). Also, participants' attitude to taking a regular Sexual Health Checkup is significantly higher among lower educated participants, among participants who had taken an STI test in the nine months before they participated in Queermasters, and among participants who reported a more positive attitude towards taking an HIV test at pretest. From the results presented in Table 8, it can also be seen that participants' perception of the social norm towards taking a regular Sexual Health Checkup is significantly higher among participants who reported not being involved in a steady relationship, among participants who had taken an STI test in the nine months before they participated in Queermasters, and among participants who reported a higher perceived social norm towards taking an HIV test at pretest. Participants' self-efficacy towards taking a regular Sexual Health Checkup is significantly higher among participants who reported having taken a (recent) HIV test in the past, and among participants who had a higher self-efficacy towards taking an HIV test at pretest. Finally, the results presented in Table 8 also show that participants' intention towards taking a regular

Table 8 Final linear regression models of attitude, social norm, self-efficacy and intention to take a regular Sexual Health Checkup (measured at three-month follow-up), with as predictors: intervention condition (0 = experimental; 1 = control), attitude, social norm, self-efficacy or intention at pretest, and background variables related to dropout ($N^{\max} = 527$)

Predictors	Attitude		Social norm		Self-efficacy		Intention	
	B	Sign.	B	Sign.	B	Sign.	B	Sign.
Intervention condition	-.082	.02	.022	.62	-.039	.30	-.061	.07
Sexual orientation	.010	.78	-.026	.56	.072	.06	.002	.96
Age	.065	.06	.084	.05	.044	.24	.099	.004
Randstad	-.047	.19	.044	.30	-.010	.80	.016	.64
Cultural background								
Educational level	-.092	.01						
Steady partner status			-.156	.001			-.111	.001
STI testing	.129	.001	.129	.006				
HIV testing					.322	<.001	.150	.001
Sexual risk behaviour								
Living area								
Attitude (pretest)	.556	<.001						
Social norm (pretest)			.534	<.001				
Self-efficacy (pretest)					.330	<.001		
Intention (pretest)							.520	<.001

All significance levels are two-tailed. Sign. = significance

sexual Health Checkup is significantly higher among older participants, among participants who reported not being involved in a steady relationship, among participants who had taken an HIV test in the nine months before they participated in Queermasters, and among participants who reported a more positive intention to take an HIV test at pretest.

Process evaluation of the intervention

As stated in the introduction section of this paper, adequate adoption and implementation of our intervention was anticipated during program development, and was ensured by the fact that it was a pre-programmed piece of software which was delivered directly to its intended users through the Internet.

The set of indicators used for the process evaluation of our intervention was related to participants' opinions about Queermasters. First of all, participants who finished their intervention, either the experimental or the control condition, were given the opportunity to rate the intervention that they were exposed to on a scale from 0 to 10. The newly developed intervention received an average score of 7.9 ($N = 598$). The intervention that served as a control condition received an average score of

7.6 ($N = 734$). Analysis of the difference between the two numbers by means of an independent sample T test indicated no significant difference ($t = .975$, $P = .330$) between the average rating of both interventions. Secondly, all participants who finished the follow-up session of Queermasters also provided us with data that reflect their general appreciation of Queermasters. Mean scores of participants in both intervention conditions on this set of five-point scales were tested for statistical differences with ANOVA. The results of these analyses are summarised in Table 9.

The results presented in Table 9 show that both interventions are evaluated positively by their respective participants since all scores are above the scale mean (note that the indicators in Table 9 are five-point scales). No statistically significant differences were found between the two intervention conditions on any of the four indicators that reflect participants' opinion about Queermasters and the respective intervention that they were exposed to. A marginally significant difference between participants in the two intervention conditions was, however, found with respect to the level at which they agreed upon advising others to participate in the intervention to which they had been exposed themselves (0 = experimental; 1 = control): participants in the experimental condition, who had been exposed to the newly developed intervention materials,

Table 9 Participants' mean score and standard error (SE) on four indicators reflecting their opinion about Queermasters ($N = 527$)

Indicator	Intervention condition		
	Experimental	Control	Sign
Participating in Queermasters was a lot of fun	4.03 (.87)	3.91 (1.0)	.14
The content of the show was very useful	4.04 (.88)	3.90 (.98)	.07
The show gave me a better view on HIV/STI testing	3.50 (1.1)	3.37 (1.1)	.19
I would advise everyone to participate in the show	4.01 (1.0)	3.77 (1.1)	.01

Items were measured on a 5-point scale: 1 = totally disagree; 5 = totally agree

were more positive on this matter compared with participants in the control condition.

Discussion and conclusion

The evaluation of a newly developed online HIV-prevention intervention is described in this paper. The intervention was systematically developed within the intervention mapping framework and aimed at promoting HIV testing among MSM in the Netherlands. Based on a set of relevant outcome variables such as Dutch MSMs' intention to get tested, actual testing behaviour and their subjective evaluation of the intervention, both the effect evaluation and the process evaluation of the intervention, which was named Queermasters, were carried out. The results of both types of evaluation have been reported in this paper.

With respect to the evaluation of the effects of Queermasters, the results are mixed and partly confirm our hypotheses and expectations about its effectiveness. In terms of motivating participants to take a Sexual Health Checkup (i.e. behavioural intention), our results at immediate posttest show that the newly developed intervention is significantly more effective in doing so, compared with the control intervention. Given the critical differences between the two interventions, this allows us to conclude that using risk communication as a method to motivate Dutch MSM to take an HIV test may be less effective in actually motivating men to do so, compared with the set of motivational strategies applied in Queermasters.

At three-month follow-up, the observed difference in motivation at the immediate posttest is not reflected in the behavioural outcome measure. According to theory, one would expect a difference in the behavioural outcome measure between the two intervention groups at three-month follow-up, in line with the significant difference in intention

at immediate posttest. One explanation for the fact that no difference in behaviour between the two intervention groups was found at three-month follow-up, may be related to the relatively short timeframe of three months between intervention and follow-up. Possibly, this timeframe is too short for participants to actually act upon their intention to get tested after exposure to the intervention material. Another explanation may be that external factors that were the same for both interventions and were not influenced by the intervention, such as the availability of sufficient testing services that are close at hand, prevented participants from translating their intention into actual behaviour. A final explanation may be that certain relevant internal determinants were not included, or fully covered in our newly developed intervention.

With respect to participants' attitude, perceived social norm, self-efficacy and intention towards taking a Sexual Health Checkup on a regular basis as measured at follow-up, the obtained results are also mixed. No difference between the experimental and the control condition was observed with respect to self-efficacy and perceived social norm. The latter is unexpected, since Queermasters included strategies to achieve a change in the participant's perception of the social norm towards taking a (regular) Sexual Health Checkup. Possibly, the Internet does not serve as a strong enough context to influence social norms. Another explanation may be that the specific strategies included in Queermasters were not suitable to establish an effect on participants' perception of the social norm regarding taking a regular Sexual Health Checkup. On the other hand, our results do provide evidence of a marginally significant difference between the two intervention conditions with respect to participants' attitude towards taking a Sexual Health Checkup on a regular basis. In addition, our results also show that participants' intention towards taking a regular Sexual Health Checkup differs substantially between the two intervention groups at three-month follow-

up. In both cases, the strategies that we included in Queermasters appear to have resulted in a positive long-term effect on both attitude and intention towards taking a regular Sexual Health Checkup. Whether this actually contributes to taking a regular Sexual Health Checkup remains unanswered within the scope of the present study, and should be subject of future research.

Some limitations of our study should be taken into account. First of all, the level of participant dropout in our study was relatively high. Although Internet studies generally suffer from relatively high levels of participant dropout over time (Bull, Lloyd, Rietmeijer, & McFarlane, 2004) we attempted to minimise this through good design, advanced tailored communication throughout Queermasters (regardless of intervention condition), personalised e-mail invitations, and incentives to encourage participants to take part in the three-month follow-up session. The relatively high level of participant dropout does not only indicate that we were not completely successful in our efforts to minimise it, but it also has consequences for the interpretation and generalisability of our findings. With respect to the latter, the analyses on dropout before randomisation show that our results may not be easily generalised to bisexual men. In both analyses, they have a significantly higher chance of dropout compared with homosexual men. It should be noted that bisexual men are generally a hard to reach group for research and prevention activities. With respect to age, another significant predictor of participant dropout before randomisation, results from the dropout analyses indicate that our findings may not be easily generalised to both older MSM, since they initially drop out significantly more, and to younger MSM, since they drop out significantly more further on in the intervention. Possibly, additional strategies are needed to ensure that both older and younger MSM are preserved in future versions of Queermasters. A further reason for concern is the higher dropout between randomisation and posttest in the experimental group. The method of analysis used, i.e. mixed regression, is valid under so-called MAR dropout and thereby much less prone to selection bias than classical ANOVA which listwise deletes any person with a missing pretest or posttest (Verbeke & Molenberghs, 2000). However, so-called MNAR missingness cannot be ruled out and may have biased our results. Unfortunately, MNAR missingness is not easily detected since it depends by the definition on unobserved variables. A final limitation of the present study that should be taken into account is the imperfect match of pretest measurement of behaviour and follow-up measurement of behaviour. Whereas at pretest, HIV-testing behaviour in the past six months was

measured, the behavioural outcome measure at follow-up concerned a timeframe of three months. A similar concern holds for the TPB measures which referred to the next three months at pretest, but to the next year at follow-up.

Recent reviews on HIV-testing determinants and behaviour among MSM confirm some of our assumptions based on earlier studies. Denial as a result of fear for the outcome of the test is indeed a relevant determinant of testing behaviour. Characteristics of the testing services indeed play an important role (Lorenc et al., 2011a). However, studies about the effectiveness of interventions promoting HIV testing and counselling among MSM are still inconclusive; only opt-out testing policies and offering rapid testing has currently been shown to increase the uptake of testing among MSM (Lorenc et al., 2011b). Currently, there is a revival of network approaches where MSM who have been tested are asked to recruit other men in their social and sexual networks, using social media (Fuqua et al., 2012). The most recent data on 'ever done an HIV test' among Dutch MSM show an increase from 73% in 2009, 75% in 2010, to 78% in 2011 (Van Empelen, Van Berkel, Roos, & Zuillhof, 2011), which is higher than before but still too low.

One of the implications of our findings for future research in the area of HIV prevention, more particularly the promotion of HIV testing, among MSM in the Netherlands relates to the apparent gap between intention on the one hand, and actual behaviour on the other hand. Future research should clarify which (set of) strategies can be applied in future interventions to effectively bridge the gap between intention and behaviour. One can think of cognitive strategies such as the formation of an implementation intention (Gollwitzer & Brandstatter, 1997; Sheeran, Webb, & Gollwitzer, 2005) or goal setting in a broader sense, but also of more practical strategies such as offering the possibility to make an online appointment for a test immediately after exposure to the intervention material on the Internet. Such strategies could be added to Queermasters and might consequently lead to the intervention being effective not only in motivating MSM to get tested but also in actually getting them tested. Future research is needed to clarify the latter.

Finally, despite the somewhat mixed results in the evaluation of the effects of our intervention, this does not imply that future development of HIV-prevention interventions should no longer be systematically planned and based on available theory and evidence. On the contrary, both early (Kalichman, Carey, & Johnson, 1996) and more recent (De Bruin, Viechtbauer, Schaalma, Kok,

Abraham, & Hospers, 2010; Van Achterberg, Huisman-de Waal, Ketelaar, Oostendorp, Jacobs, & Wollersheim, 2011; Van Empelen, et al., 2003) reviews on the effectiveness of health promotion programs have consistently shown that systematically developed interventions have the highest chance of being effective in achieving their goals. As such, the results obtained in our study illustrate that the systematic development of an HIV-prevention intervention does not guarantee that it will be effective in achieving all its goals and

objectives. Finding out that an intervention does not completely result in the expected effects, on the basis of good experimental research, should thus motivate both researchers and health promotion planners to further adapt the content of the intervention in an informed and theory- and evidence-based way.

Competing interests

The authors declare that they have no competing interests.

References

- Ajzen, I. (1991). The Theory of Planned Behavior. *Organizational Behavior & Human Decision Processes*, 50, 179-211.
- Bartholomew, L. K., Parcel, G. S., Kok, G., Gottlieb, N. H., & Fernández, M. E. (2011). *Planning health promotion programs: an Intervention Mapping approach*. 3rd edition. San Francisco, CA: Jossey-Bass.
- Bull, S. S., Lloyd, L., Rietmeijer, C., & McFarlane, M. (2004). Recruitment and retention of an online sample for an HIV prevention intervention targeting men who have sex with men: the Smart Sex Quest Project. *Aids Care*, 16, 931-943.
- De Bruin, M., Viechtbauer, W., Schaalma, H. P., Kok, G., Abraham, C., & Hospers, H. J. (2010). Standard care impact on effects of highly active antiretroviral therapy adherence interventions: a meta-analysis of randomized controlled trials. *Archives of Internal Medicine*, 170, 240-50.
- Field, A. P. (2005). *Discovering statistics using SPSS*. 2nd edition. London: Sage.
- Fuqua, V., Chen, Y-H, Packer, T., Dowling, T., Ick, T. O., Nguyen, B., Colfax, G. N. & Raymond, H. F. (2012). Using social networks to reach black MSM for HIV testing and linkage to care. *AIDS & Behavior*, 16, 256-265.
- Gezondheidsraad, Beraadsgroep Infectie en Immunititeit (1999). *Herziening van het HIV-testbeleid [A revision of the HIV-testing policy]* Publicatie nr. 1999/02. Den Haag: Gezondheidsraad. <http://www.webcitation.org/5g9CTfo83>.
- Gollwitzer, P. M., & Brandstaetter, V. (1997). Implementation intentions and effective goal pursuit. *Journal of Personality & Social Psychology*, 73, 186-199.
- Hospers, H. J., Dörfler, T. T., & Zuilhof, W. (2008). *Schorer Monitor 2008*. Amsterdam: Schorer.
- Hospers, H. J., Dörfler, T. T., Zuilhof, W., & Nijman, A. M. (2007). *Schorer Monitor 2007*. Amsterdam: Schorer.
- Hogeweg, J. A., & Hospers, H. J. (2000). *Monitoronderzoek 2000*. Maastricht: Universiteit Maastricht.
- Ives, N. J., Gazzard, B. G., & Easterbrook, P. J. (2001). The changing pattern of AIDS-defining illnesses with the introduction of Highly Active Antiretroviral Therapy in a London clinic. *Journal of Infection*, 42, 134-139.
- Kalichman, S. C., Carey, M. P., & Johnson, B. T. (1996). Prevention of sexually transmitted HIV infection: A meta-analytic review of the behavioral outcome literature. *Annals of Behavioral Medicine*, 18, 6-15.
- Kok, G., Harterink, P., Vriens, P., De Zwart, O. & Hospers, H. J. (2006). The Gay Cruise: Developing theory- and evidence-based Internet HIV-prevention. *Sexuality Research and Social Policy: Journal of NSRC*, 3, 52-67. <http://pubs.cpha.ca/PDF/P44/24744.pdf>
- Kok, G., Schaalma, H., Ruiter, R. A. C., van Empelen, P., & Brug, J. (2004). Intervention Mapping: a protocol for applying health psychology theory to prevention programmes. *Journal of Health Psychology*, 9, 95-98.
- Lauby, J. L., Bond, L., Erğolu, D., & Batson, H. (2006). Decisional balance, perceived risk and hiv testing practices. *AIDS & Behavior*, 10, 83-91.
- Lorenc, T., Marrero-Guillemón, I., Llewellyn, A., Aggleton, P., Cooper, C., Lehmann, A., & Lindsay, C. (2011a). HIV testing among men who have sex with men (MSM): systematic review of qualitative evidence. *Health Education Research*, 26, 834-846.
- Lorenc, T., Marrero-Guillemón, I., Aggleton, P., Cooper, C., Llewellyn, A., Lehmann, A., & Lindsay, C. (2011b). Promoting the uptake of HIV testing among men who have sex with men: systematic review of effectiveness and cost-effectiveness. *Sexually Transmitted Diseases*, 87, 272-278.
- Marks, G., Crepaz, N., Senterfitt, W., & Janssen, R-S. (2005). Meta-analysis of high-risk sexual behavior in persons aware and unaware they are infected with HIV in the United States: implications for HIV prevention programs. *Journal of Acquired Immune Deficiency Syndromes*, 39, 446-453.
- Matic, S., Lazarus, J. V., & Donoghoe, M. C. (2006). *HIV/AIDS in Europe: moving from death sentence to chronic disease management*. Denmark: World Health Organization.
- Mikolajczak, J., Hospers, H. J. & Kok, G. (2006). Reasons for not taking an HIV-test among untested men who have sex with men: An Internet study. *AIDS and Behavior*, 10, 431-435.
- Mikolajczak, J., Kok, G., & Hospers, H. J. (2008). Queermasters:

- developing a theory- and evidence-based Internet HIV-prevention intervention to promote HIV-testing among men who have sex with men (MSM). *Applied Psychology: An International Review*, 57, 681-697. [may be requested at: g.kok@maastrichtuniversity.nl]
- Mikolajczak, J., Van Kesteren, N., Hospers, H. J., Kok, G. (2004). Een kwalitatief onderzoek naar redenen om niet te testen op HIV bij Nederlandse mannen die seks hebben met mannen [A qualitative study into reasons for not taking an HIV-test among Dutch men who have sex with men]. *TSG: Tijdschrift voor Gezondheidswetenschappen*, 7, 450-456.
- NCHSR, National Center in HIV Social Research. (2005). *Annual report of behaviour 2005*. Sydney: University of New South Wales.
- Ruiter, R. A. C., Verplanken, B., De Cremer, D., & Kok, G. (2004). Danger control and fear control in response to fear appeals: the role of need for cognition. *Basic and Applied Social Psychology* 2004, 26, 13-24.
- Saunders, D. S., & Burgoyne, R. W. (2000). Evaluating health related wellbeing outcomes among outpatients with human immunodeficiency virus infection in the HAART era. *International Journal of STD & AIDS*, 13, 683-690.
- Schaalma, H. & Kok, G. (2009). Decoding health education interventions: The times are a-changin'. *Psychology & Health*, 24, 5-9.
- Schafer, J. L., & Graham, J. W. (2002). Missing data: our view of the state of the art. *Psychological Methods*, 7, 147-177.
- Sheeran, P., Webb, T. L., & Gollwitzer, P. M. (2005). The interplay between goal intentions and implementation intentions. *Personality & Social Psychology Bulletin*, 31, 87-98.
- Tweede Kamer, vergaderjaar 2003-2004 (2003). *Seksueel overdraagbare aandoeningen (soa): Kamerstuk 29 220 1 [Sexually Transmitted Diseases (STD)]*. Den Haag: Ministerie van Volksgezondheid Welzijn en Sport. <http://www.webcitation.org/5g9Dr9eBq>.
- Van Achterberg, T., Huisman-de Waal, G. G. J., Ketelaar, N. A. B. M., Oostendorp, R. A., Jacobs, J. E., & Wollersheim, H. C. H. (2011). How to promote healthy behavior in patients? A review of systematic reviews. *Health Promotion International*, 26, 148-62.
- Van Breukelen, G. J. P. (2006). ANCOVA vs. change from baseline: more power in randomized studies, more bias in nonrandomized studies. *Journal of Clinical Epidemiology*, 59, 920-925.
- Van Empelen, P., Kok, G., Van Kesteren, N. M. C., Van den Borne, B., Bos, A., & Schaalma, H. P. (2003). Effective methods to change sex-risk behavior among drug users: a review of psychosocial interventions. *Social Science & Medicine*, 57, 1593-1608.
- Van Empelen, P., Van Berkel, M., Roos, E., & Zuilhof, W. (2011). *Schorer Monitor 2011*. Amsterdam: Schorer.
- Verbeke, G., & Molenberghs, G. (2000). *Linear mixed models for longitudinal data*. New York: Springer-Verlag.
- Weinhardt, L. S., Carey, M. P., Johnson, B. T., & Bickham, N. L. (1999). Effects of HIV counseling and testing on sexual risk behavior: a meta-analytic review of published research, 1985-1997. *American Journal of Public Health*, 89, 1397-1405.
- Wolfers, M. E. G., Van den Hoek, C., Brug, J., & De Zwart, O. (2007). Using Intervention Mapping to develop a programme to prevent sexually transmittable infections, including HIV, among heterosexual migrant men. *BMC Public Health*, 7:141. <http://www.biomedcentral.com/content/pdf/1471-2458-7-141.pdf>

JOCHEN MIKOLAJCZAK

Social psychologist with a PhD from Maastricht University. As a researcher focussing on public health, prevention and behaviour change, he first worked at the Netherlands Organization for Applied Scientific Research (TNO) and currently works at the National Institute for Public Health and the Environment (RIVM).

E-mail: jochen.mikolajczak@rivm.nl

GERARD VAN BREUKELLEN

Obtained his MSc and PhD in mathematical psychology at the Radboud University of Nijmegen. He is currently associate professor of statistics at Maastricht University. His past work was about psychometric models for response times. His present publications are mainly about the design and analysis of intervention studies.

E-mail: gerard.vbreukelen@stat.unimaas.nl

GERJO KOK

Social psychologist with an MSc and PhD from the University of Groningen. He was professor of health promotion at Maastricht University in 1984-1998. Since 1998 he is professor of applied psychology at Maastricht. His publications concern the application of social psychological theory to planned behaviour change.

E-mail: g.kok@maastrichtuniversity.nl

HARM HOSPERS

Received his MSc in personality psychology at the University of Groningen and his PhD at Maastricht University. Since 2009 he is professor of applied health psychology and Dean of University College Maastricht. His main research interest is the development, implementation and evaluation of HIV prevention programs.

E-mail: h.hospers@maastrichtuniversity.nl

Psychological care in cancer patients and their caregivers: Who gets help, why, when, and how?

The main purpose of this study was to examine type of referral and demographic, clinical, and treatment characteristics of patients and caregivers referred to psychological care. Psychologists accredited within the Psychology Network of IKNL (the Comprehensive Cancer Centre the Netherlands), location Amsterdam, collected data regarding type of clients, age, gender, cancer-related aspects, referring profession, referral indication, time of referral, psychological care setting, psychological intervention, number of sessions, and duration of intervention. In total 1026 clients were included: 629 patients and 357 caregivers. In most cases, the general practitioner was the referring professional. Most patients were treated with curative intent, most often for breast cancer. The most common reason for referral of caregivers was when the patient was in the palliative phase or had died. Clients were often referred regarding problems with physical difficulties, relationships, meaning-making, anxiety, and mood disorder. Various psychological interventions were applied. A psychology network caters for the need for psychological care by patients and caregivers and contributes to optimising the organisation of supportive cancer care.

Where: Netherlands Journal of Psychology, Volume 67, 36-42

Received 11 March 2012; Accepted 11 August 2012

Keywords: Cancer; Oncology; Psychological care; Referral; Supportive cancer care; Caregivers

Authors: Sanne Krul*, Marjet Docter**, Christine Brouwer-Dudok de Wit**, and Irma M. Verdonck-de Leeuw*,***

* Department of Clinical Psychology, VU University, Amsterdam, the Netherlands,

** Comprehensive Cancer Centre the Netherlands, Amsterdam, the Netherlands,

*** Department of Otolaryngology – Head & Neck Surgery, VU University Medical Center, Amsterdam, the Netherlands

Correspondence to: Irma M. Verdonck-de Leeuw, Department of Clinical Psychology, VU University, Van der Boechorststraat 1, 1081 BT Amsterdam, the Netherlands, e-mail: im.verdonck@vumc.nl

Many cancer patients suffer from psychological distress (Jacobsen, 2007; Holland et al., 2010). Symptoms of depression, anxiety, fatigue, and insomnia are common side effects of cancer and its treatment, which also occur in long-term survivors (Foster, Wright, Hill, Hopkinson, & Roffe, 2009). Additionally, cancer patients may struggle with meaning-making of their threatened life expectancy (Breitbart & Alici, 2009; LeMay & Wilson, 2008). Not only cancer patients but also their caregivers are at risk of developing psychological distress, and may need psychological support (Siminoff, Wilson-Genderson, & Baker, 2010; Verdonck-de Leeuw, Eerenstein, Van der Linden, Kuik, De Bree, & Leemans, 2007; Pitceathly & Maguire, 2003). There is growing interest in using patient-reported outcomes to screen for psychosocial or physical problems in routine clinical practice (Jacobsen, 2007; Holland et al., 2010; Snyder et al., 2011; Carlson, Groff, Maciejewski, & Bultz,

2010; Luckett, Butow, & King, 2009; Verdonck-de Leeuw et al. 2009; De Bree, Verdonck-de Leeuw, Keizer, Houffelaar, & Leemans, 2008), and several studies have shown that the use of patient-reported outcomes facilitates communication about quality of life between doctors and cancer patients (Velikova et al., 2004; Detmar, Muller, Schornagel, Wever, & Aaronson, 2002; McLachlan et al., 2001; Taenzer et al., 2000). Screening the caregivers of cancer patients for distress is also an efficient approach to integrate family members in the program of care (Zwahlen, Hagenbuch, Carley, Recklitis, & Buchi, 2008). In many countries, government policy statements, and guidelines such as the Dutch guideline ‘Screening for the need for psychosocial care’ and the USA National Comprehensive Cancer Network guideline for psychosocial distress reflect broad scientific and social support for a structured, integrated approach to psychosocial care in cancer patients and their families. During the past years,

screening instruments have been implemented in clinical practice in many oncological settings.

Screening alone, however, will not lead to improved quality of life, which is obviously also dependent on the need for, referral to and success of intervention (Palmer, Van Scheppingen, & Coyne, 2011; Van Scheppingen et al., 2011). An increased need for and use of psychological care is expected in the near future, due to an increased number of cancer patients living longer with cancer. Optimal anticipation to this increased need is hampered because at present little is known about referral to and type of psychosocial care in clinical practice. The goal of this study is to examine type of referral and demographic, clinical, and treatment characteristics of patients and caregivers referred to psychological care in clinical practice. Results may contribute to optimising the organisation of psychological cancer care.

Methods

Participants

IKNL (Comprehensive Cancer Centre The Netherlands) is a network organisation and knowledge and healthcare improvement institute. IKNL provides direction to the integral approach and continuous improvement in oncological and palliative chain care. Through this network, they foster expertise and multidisciplinary cohesion in the delivery of cancer care and other associated areas. Comprehensive care involves all aspects of care: medical care, allied health services, and psychosocial care, and is therefore by definition multidisciplinary. The services of tIKNL are directed towards improving the professional and organisational quality of care. IKNL focuses on professional health care workers. The aim is to provide care tailored to the individual patient's needs and to ensure that the care provided by the various disciplines is well coordinated. IKNL location Amsterdam has a catchment area of 19 hospitals. The incidence of patients diagnosed with cancer was 16,248 in the Amsterdam area in 2009 (Dutch Cancer Registration, 2011). In 1999, a network of psychologists specialised in psychosocial cancer care was set up in the northwest area of the Netherlands. Psychologists have to meet certain requirements to become a member. They need to be registered according to the Dutch accreditation system and have a Master's Degree in Psychology. Furthermore, they must have completed a course on specialised psychological care for cancer patients and their caregivers. Also, they have to attend at least two out of four annual meetings of the network keeping their expertise up to date. IKNL provides advice and support to psychologists participating in this CCC Amsterdam

Psychologists Network (IKNL-PN) and the list of psychologists is managed by a IKNL employee. The participating psychologists are included in a referral guide facilitating referral by other care professionals such as medical specialists and general practitioners. Psychologists in the network agreed to register data enabling evaluation of their psychological care provided to cancer patients and caregivers.

Materials

From 2002 to 2009, registration data were collected regarding psychological care by in total 52 psychologists participating in the IKNL-PN; it is estimated that these 52 psychologists represent 15% of all psychologists in the area of Amsterdam. The psychologists registered the data per patient on a structured form including: type of client (patient or caregiver (partners, parents, children, or siblings)), age, sex, type of tumour, referring profession, referral indication, type of psychological intervention, number of sessions, and duration of intervention. From 2006 onwards, the following variables were added: psychological care setting, disease phase and from 2008 onwards whether the cancer patient was being treated with curative intent or was in the palliative phase of the disease. All data were gathered through an online questionnaire.

Analyses

Statistical analyses were performed by means of the Statistical Package for the Social Sciences (SPSS) 18.0. Descriptive statistics were generated for the range of outcome variables. The primary outcome variables were type of client (patient or caregiver), age, sex, cancer-related aspects (type of tumour, disease phase, treatment intent), referring profession, referral indication, time of referral, type of psychological care setting, type of psychological intervention, number of sessions, and duration of intervention.

Results

Study cohort

The initial cohort consisted of 1026 clients who were referred to psychological care during the inclusion period (2002-2009). For 40 clients, there was no mention of whether the participant was a patient or caregiver, leaving a study cohort of 986 clients: 629 cancer patients (64%) and 357 caregivers (36%). Of the cancer patients, 81% were female and 19% were male, versus 72% female and 28% male caregivers. Mean age of the cancer patients was 50 years (range 19-80); mean age of the caregivers was 47 years (range 19-83). An overview of the study cohort is given in [Table 1](#).

Table 1 Demographic characteristics

	Patients	Caregivers
Male	19.4%	27.7%
Female	80.6%	72.3%
Age (years)	Mean 50.5 (SD=12.2)	Mean 46.6 (SD=13.7)

Cancer-related characteristics

In patients, the most common type of cancer was breast cancer (46%); other frequently reported types of cancer were colon cancer (7%), lung cancer (6%), brain tumour (4%), non-Hodgkin's disease (4%) and Hodgkin's disease (3%). Breast cancer was also the most common type of cancer in the group of caregivers of cancer patients: 25% cared for a patient with breast cancer, 13% for a patient with lung cancer, 9% for colon cancer, 10% for brain tumour, and 4% for Hodgkin's disease. An overview of type of cancer among patients and caregivers is given in [Table 2](#).

Table 2 Type of cancer

	Patients	Caregivers
Breast cancer	281 (46.2%)	83 (25.6%)
Gynaecological cancer	35 (5.8%)	12 (3.7%)
Hodgkin's disease	17 (2.8%)	13 (4.0%)
Non-Hodgkin's disease	24 (4.0%)	8 (2.5%)
Acute leukaemia	5 (0.8%)	14 (4.3%)
Chronic leukaemia	6 (1%)	4 (1.2%)
Colorectal cancer	44 (7.2%)	29 (9.0%)
Lung cancer	39 (6.4%)	44 (13.6%)
Brain tumour	27 (4.4%)	34 (10.5%)
Skin cancer	22 (3.6%)	2 (0.6%)
Prostate cancer	19 (3.1%)	8 (2.5%)
Stomach cancer	8 (1.3%)	10 (3.1%)
Kidney cancer	8 (1.3%)	5 (1.5%)
Pancreatic cancer	7 (1.2%)	11 (3.4%)
Testicle cancer	5 (0.8%)	2 (0.6%)
Head and neck cancer	3 (0.5%)	11 (3.4%)
Other	58 (9.6%)	34 (10.5%)

Results regarding disease phase are shown in [Table 3](#). Registration started in 2006 (data are available for 414 cancer patients and 233 caregivers) and patients were categorised into 'acute phase', 'chronic phase', 'recurrence phase', 'deceased' or 'unknown'. The majority of the cancer patients were in the chronic phase when they were referred to psychological care (66%). The most common reason why caregivers were referred to psychological care was after a loved one had died (36%) or was in the chronic phase of the disease (35%).

In 2008 and 2009 it was also registered whether a patient was treated with curative or palliative intent (data are available for 177 cancer patients and 113 caregivers). The majority of the patients were treated with curative intent (74%). Approximately half of the caregivers were caring for a patient in the palliative phase of the disease (53%) while 47% were caring for a patient being treated with curative intent (47%).

Referral

Results regarding referring profession are shown in [Table 4](#). Cancer patients were mostly referred to psychological care by the general practitioner (39%). Other professionals referring patients were surgical, radiation or medical oncologists (13%), nurses (10%), social workers (6%), and physiotherapists (5%). Furthermore, some cancer patients asked for help themselves (14%). The majority of the caregivers were referred by the general practitioner (70%); 11% asked for help themselves.

Among patients, the most common referral indications ([Table 4](#)) were problems regarding coping with physical symptoms (56%), problems with their partner, family or relatives (35%), meaning-making (33%), anxiety disorders (30%) and mood disorders (24%), and problems regarding work or school (11%). Among the caregivers the most common indications were problems regarding their relationship with the partner, family or relatives (47%), mood disorders (31%), problems regarding

Table 3 Disease phase and treatment intent

	Patients	Caregivers
Acute phase	81 (19.9%)	39 (17.3%)
Chronic phase	268 (65.8%)	80 (35.4%)
Recurrence	34 (8.4%)	20 (8.8%)
After decease		82 (36.3%)
Unknown	24 (5.9%)	5 (2.2%)
Curative treatment	112 (73.3%)	25 (47.2%)
Palliative treatment	40 (26.3%)	28 (52.8%)

Table 4 Type of referring profession and referral indication

Referring profession	Patients	Caregivers
General practitioner	235 (39.4%)	237 (69.7%)
Medical (oncology) specialist	77 (12.9%)	16 (4.7%)
Nurse	61 (10.2%)	10 (2.9%)
Social worker	36 (6.0%)	9 (2.6%)
Physiotherapist	32 (5.4%)	0
Medical officer	14 (2.4%)	5 (1.5%)
Psychologist	19 (3.2%)	8 (2.4%)
Own initiative	81 (13.6%)	38 (11.2%)
Other	41 (6.9%)	17 (5.0%)
Referral indication	Patients	Caregivers
Mood disorders	154 (24.5%)	111 (31.1%)
Anxiety disorders	191 (30.4%)	67 (18.8%)
Coping with physical symptoms	354 (56.3%)	59 (16.5%)
Cognitive disorders	23 (3.7%)	2 (0.6%)
Identity problems	20 (3.2%)	3 (0.8%)
Educational problems	1 (0.2%)	1 (0.3%)
Problems regarding to partner, children, family	228 (36.3%)	180 (50.4%)
Problems regarding work or school	68 (10.8%)	43 (12.0%)
Posttraumatic stress disorder (other than cancer)	14 (2.2%)	5 (1.4%)
Addiction	6 (1.0%)	2 (0.6%)
Meaning-making	209 (33.2%)	95 (26.6%)
Sexual problems	5 (0.8%)	1 (0.3%)
Other	131 (20.8%)	98 (27.5%)

meaning-making (27%), anxiety disorders (19%), coping with physical complaints such as stress-related symptoms (17%), and problems regarding work or school (12%).

Psychological care

The mean number of sessions was 9.0 ($SD = 9.4$) for patients. The mean number of weeks was 20.4 ($SD = 25$). For caregivers the mean number of sessions was 8.8 ($SD = 9.1$) and the mean number of weeks was 24.1 ($SD = 27.3$). In the Dutch healthcare insurance system from 2006 onwards, short-term psychological care is covered by all insurance companies with a maximum of eight sessions.

Results regarding type of psychological cancer care are shown in Table 5. Psychological care in cancer

patients included psycho-education (33%), exploring the emotional impact of cancer (29%), coping with the disease (29%), cognitive behavioural therapy in general (29%), exploring traumatic experiences from the past (22%), relaxation exercises (20%), creative therapy (8%), visualisation (6%), and hypnosis (0.6%). In caregivers, most attention was paid to reactualised traumatic experiences from the past (37%), cognitive behavioural therapy in general (35%), psycho-education (25%), exploring the emotional impact of the cancer (21%), coping with cancer (10%), relaxation exercises (8%), creative therapy (2%) and visualisation (2%).

Regarding the psychological care setting (Table 5), both patients (70%) and caregivers (68%) were generally seen individually; 13% of the patients and 12% of the caregivers were seen as a couple, and 9% of the patients joined group therapy.

Discussion

In the present study, referral patterns (type of referred client, type of referring profession, time of referral, referral indication) and type and setting of psychosocial care were investigated in a cohort of 986 clients (629 cancer patients and 357 caregivers). Most referred cancer patients were women being treated for breast cancer and most referred caregivers were male spouses of breast cancer patients. The mean age of the referred patients in the present study was younger (50 years) compared with the mean age of cancer patients in general (>60 years). These findings correspond with earlier studies reporting that referral to psychosocial care in cancer patients is predicted by younger age and female gender (Ellis et al., 2008; Alter, 2009; McNamara & Rosenwax, 2010; Holtlander, 2008).

Most cancer patients were treated with curative intent and in the chronic phase of the disease, indicating they were cancer survivors. Patients were often referred by the general practitioner but also by medical specialists or nurses. Also, some patients contacted psychologists themselves. In contrast, referral of caregivers more often occurred when the patient was in the palliative phase or had died. The general practitioners referred the majority of the caregivers. Earlier research also revealed that losing a spouse is predictive for referral to psychosocial care, especially when the deceased patient did not die in their preferred place of death (McNamara & Rosenwax, 2010; Holtlander, 2008). Brazil, Sussman, Bainbridge and Whelan (2010) investigated the role of general practitioners in supportive cancer care: they reported that general practitioners tend to see themselves as part of a coordinating team in end-of-life care, whereas they

Table 5 Type and setting of psychological cancer care

Type of care	Patients	Caregivers
Psycho-education	205 (32.6%)	91 (25.5%)
Cognitive therapy	179 (28.5%)	125 (35.0%)
Exploration of the impact of cancer	185 (29.4%)	76 (21.3%)
Coping with the traumatic event of having cancer	183 (29.1%)	36 (10.1%)
Exploration of (actualised) events from the past	141 (22.4%)	132 (37.0%)
Relaxation exercises	126 (20.0%)	27 (7.6%)
Visualisation	38 (6.0%)	6 (1.7%)
Creative therapy	51 (8.1%)	8 (2.2%)
Hypnosis	4 (0.6%)	0
Other	142 (22.6%)	84 (23.5%)
Setting	Patients	Caregivers
Individual	439 (69.8%)	241 (67.5%)
Couple	81 (12.9%)	42 (11.8%)
Family	4 (0.6%)	5 (1.4%)
Group	57 (9.1%)	4 (1.1%)
Other	0	1 (0.3%)

are more likely defer their responsibility for supportive care to the medical specialist or hospital in more recently diagnosed patients. Ahmed, Bestall, Ahmedzai, Payne, Clark, and Noble (2004) identified barriers to referral and access to psychological care, including a lack of knowledge and education among health professionals and a lack of standardised referral criteria. Especially patients from minority ethnic communities, older people, and socially deprived people, such as the homeless, were not referred early enough. Studies from Japan revealed that caregivers often suffer from an adjustment disorder followed by major depression and that an adequate support system for family members of cancer patients is lacking (Akechi et al., 2006; Asai et al., 2008).

In the present study, the most common indication for referring cancer patients was problems with coping with physical impairment, problems with relationships, meaning-making, and anxiety or mood disorder. Referral indication in caregivers was most often connected with problems with relationships, mood disorders, meaning-making, and anxiety disorders. In the present study, most patients and caregivers received therapy in an individual setting. A variety of psychological care modalities were used including psycho-education,

relaxation exercises, and cognitive behavioural therapy. Psychosocial cancer care has proven to be beneficial for patients with cancer and their caregivers. A recent meta-analysis focusing on patients with somatic diseases including cancer, revealed that psychological intervention in cancer patients with comorbid depressive symptoms is as effective as in otherwise healthy patients (Van Straten, Geraedts, Verdonck-de Leeuw, Andersson, & Cuijpers, 2010). Behavioural therapy is found to have a positive effect on quality of life and diminishing depression and anxiety, also for cancer survivors (Osborn, Demoncada, & Feuerstein, 2006; Uitterhoeve et al., 2004). Cognitive behavioural therapy is widely studied and helps patients with problem solving, reframing thoughts, constructive coping, and relaxation. Psychosocial interventions are helpful in relieving cancer-related distress, not only for the patients, but also for their caregivers (Weis, 2003). Therapy for family and couples can address illness-related problems and conflicts, and sexual problems. Psychological support such as family-focused grief therapy may reduce the risk of complicated grief (Grassi, 2007).

However, not many cancer patients are having the benefit of psychological support (Verdonck-de Leeuw et al., 2009; Van Scheppingen et al., 2011). Also in the present study on referral to and type of psychological support in a large cohort of over 1000 patients and caregivers, it is estimated that this is only a fragment (less than 1%) of the total target group of the network of psychologists in Amsterdam involved in the study. Of course, patients with a need for psychological support may have been referred to other psychologists not involved in this network of psychologists participating in the present study; in the Netherlands, cancer patients are most likely to be treated by hospital psychologists or by social workers. Still, there seems to be a discrepancy between the need for psychological care (approximately 20% of cancer patients (Van Scheppingen et al., 2011)) and the psychological care offered to patients in clinical practice. This discrepancy may increase in the near future and should be anticipated by optimising healthcare systems. The Chronic Care Model identifies essential elements of high-quality healthcare systems: the health delivery system (promoting care in an effective, efficient manner), clinical information system (facilitating efficient and effective care), decision support (consistent with scientific evidence and patient preferences), self-management support (empower patients to manage their health and healthcare), and the community (mobilise community resources to meet the needs of patients) (Coleman, Austin, Brach, & Wagner, 2009). Organising psychological care according

to the chronic care model also improves disease management in cancer patients. Disease management refers to a system of coordinated comprehensive care along the continuum of the disease across healthcare delivery systems, with a special focus on self-management. In disease management programmes, healthcare by different professionals and in different institutions is better tuned and coordinated. From the present study, it can be concluded that a psychology network caters for the needs of cancer patients and their caregivers. Incorporation of such networks may contribute to the organisation of psychological cancer care according to disease-management principles.

Acknowledgements

The authors acknowledge the participating psychologists in the network of psychologists of the Comprehensive Cancer Centre Amsterdam for their efforts to register research data.

Ethical standards: This study was performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki. All subjects gave informed consent.

Conflict of interest: None of the authors have a financial relationship, they had full control of all primary data and they agree to allow the journal to review the data.

References

- Ahmed, N., Bestall, J. C., Ahmedzai, S. H., Payne, S. A., Clark, D., & Noble, B. (2004). Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliative Medicine*, *18*, 525-542.
- Akechi, T., Akizuki, N., Okamura, M., Shimizu, K., Oba, A., Ito, T., Yoshikawa, E., Nakano, T., Inagaki, M., & Uchitomi, Y. (2006). Psychological distress experienced by families of cancer patients: preliminary findings from psychiatric consultation of a cancer centre hospital. *Japanese Journal of Clinical Oncology*, *36*, 329-332.
- Alter, C. L. (2009). Predictors of referral for psychosocial services: recommendations from the institute of medicine report – cancer care for the whole patient. *Journal of Clinical Oncology*, *27*, 659-660.
- Asai, M., Akechi, T., Nakano, T., Shimizu, K., Umezawa, S., Akizuki, N., & Uchitomi, Y. (2008). Psychiatric disorders and background characteristics of cancer patients' family members referred to psychiatric consultation service at National Cancer Centre Hospitals in Japan. *Palliative Supportive Care*, *6*, 225-230.
- Brazil, K., Sussman, J., Bainbridge, D., & Whelan, T. (2010). Who is responsible? The role of family physicians in the provision of supportive care. *Journal of Oncology Practice*, *6*, 19-24.
- Breitbart, W. S., & Alici, Y. (2009). Psycho-Oncology. *Harvard Review of Psychiatry*, *17*, 361-376.
- Carlson, L. E., Groff, S. L., Maciejewski, O., & Bultz, B. D. (2010). Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *Journal of Clinical Oncology*, *28*, 4884-4891.
- Coleman, K., Austin, B. T., Brach, C., & Wagner, E. H. (2009). Evidence on the Chronic Care Model in the new millennium. *Health Affairs (Millwood)*, *28*, 75-85.
- De Bree, R., Verdonck-de Leeuw, I. M., Keizer, A. L., Houffelaar, A., & Leemans, C. R. (2008). Touch screen computer-assisted health-related quality of life and distress data collection in head and neck cancer patients. *Clinical Otolaryngology*, *33*, 138-142.
- Detmar, S. B., Muller, M. J., Schornagel, J. H., Wever, L. D., & Aaronson, N. K. (2002). Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *Journal of the American Medical Association*, *288*, 3027-3034.
- Ellis, J., Lin, J., Walsh, A., Lo, C., Shepherd, F. A., Moore, M., Li M., Gagliese L., Zimmermann C., & Rodin, G. (2008). Predictors of referral for specialized psychosocial oncology care in patients with metastatic cancer: the contributions of age, distress, and marital status. *Journal of Clinical Oncology*, *27*, 699-705.
- Foster, C., Wright, D., Hill, H., Hopkinson, J., & Roffe, L. (2009). Psychosocial implications of living 5 years or more following a cancer diagnosis: a systematic review of the research evidence. *European Journal of Cancer Care*, *18*, 223-247.
- Grassi, L. (2007). Bereavement in families with relatives dying of cancer. *Current Opinion in Supportive and Palliative Care*, *1*, 43-49.
- Holland, J. C., Andersen, B., Breitbart, W. S., Compas, B., Dudley, M. M., Fleishman, S., Fulcher C. D., Greenberg D. B., Greiner C. B., Handzo G. F., Hoofring L., Jacobsen P. B., Knight S. J., Learson K., Levy M. H., Loscalzo M. J., Manne S., McAllister-Black R., Riba M. B., Roper K., Valentine A. D., Wagner L. I., & Zevon M. A.; NCCN Distress Management Panel. (2010). Distress management. *Journal of the National Comprehensive Cancer Network*, *8*, 448-485.
- Holtslander, L. F. (2008). Caring for bereaved family caregivers: analyzing the context of care. *Clinical Journal of Oncology Nursing*, *12*, 501-506.
- Jacobsen, P. B. (2007). Screening for psychological distress in cancer patients: challenges and opportunities. *Journal of Clinical Oncology*, *25*, 4526-4527.
- LeMay, K., & Wilson, K. G. (2008). Treatment of existential distress in life threatening illness: a review of manualized interventions. *Clinical Psychology Review*, *28*, 472-493.
- Luckett, T., Butow, P. N., & King, M. T. (2009). Improving patient outcomes through the routine use of patient-reported data in cancer clinics: future directions. *Psychooncology*, *18*, 1129-1138.

- McLachlan, S. A., Allenby, A., Matthews, J., Wirth, A., Kissane, D., Bishop, M., & Zalcberg, J. (2001). Randomized trial of coordinated psychosocial interventions based on patient self-assessments versus standard care to improve the psychosocial functioning of patients with cancer. *Journal of Clinical Oncology, 19*, 4117-4125.
- McNamara, B., & Rosenwax, L. (2010). Which carers of family members at the end of life need more support from health services and why? *Social Science and Medicine, 70*, 1035-1041.
- Osborn, R. L., Demoncada, A. C., & Feuerstein, M. (2006). Psychosocial interventions for depression, anxiety, and quality of life in cancer survivors: meta-analyses. *International Journal of Psychiatry in Medicine, 36*, 13-34.
- Palmer, S. C., Van Scheppingen, C., & Coyne, J. C. (2011). Clinical trial did not demonstrate benefits of screening patients with cancer for distress. *Journal of Clinical Oncology, 29*, 277-278.
- Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: a review. *European Journal of Cancer, 39*, 1517-1524.
- Van Scheppingen, C., Schroevers, M. J., Smink, A., Linden, Y. M. Van der, Mul, V. E., Langendijk, J. A., Coyne J.C., & Sanderman, R. (2011). Does screening for distress efficiently uncover meetable unmet needs in cancer patients? *Psychooncology, 20*, 655-663.
- Siminoff, L. A., Wilson-Genderson, M., & Baker, S. (2010). Depressive symptoms in lung cancer patients and their family caregivers and the influence of family environment. *Psychooncology, 19*, 1285-1293.
- Snyder, C. F., Blackford, A. L., Aaronson, N. K., Detmar, S. B., Carducci, M. A., Brundage, M. D., & Wu, A. W. (2011). Can Patient-Reported Outcome Measures Identify Cancer Patients' Most Bothersome Issues? *Journal of Clinical Oncology, 29*, 1216-1220.
- Taenzer, P., Bultz, B. D., Carlson, L. E., Specia, M., DeGagne, T., Olson, K., Doll, R., & Rosberger, Z. (2000). Impact of computerized quality of life screening on physician behaviour and patient satisfaction in lung cancer outpatients. *Psychooncology, 9*, 203-213.
- Uitterhoeve, R. J., Vernoooy, M., Litjens, M., Potting, K., Bensing, J., De Mulder, P., & Van Achterberg, T. (2004). Psychosocial interventions for patients with advanced cancer – a systematic review of the literature. *British Journal of Cancer, 91*, 1050-1062.
- Van Straten, A., Geraedts, A., Verdonck-de Leeuw, I. M., Andersson, G., & Cuijpers, P. (2010). Psychological treatment of depressive symptoms in patients with medical disorders: a meta-analysis. *Journal of Psychosomatic Research, 69*, 23-32.
- Velikova, G., Booth, L., Smith, A. B., Brown, P. M., Lynch, P., Brown, J. M., & Selby, P. J. (2004). Measuring quality of life in routine oncology practice improves communication and patient well-being: a randomized controlled trial. *Journal of Clinical Oncology, 22*, 714-724.
- Verdonck-de Leeuw, I. M., Eerenstein, S. E., Van der Linden, M. H., Kuik, D. J., De Bree, R., & Leemans, C. R. (2007). Distress in spouses and patients after treatment for head and neck cancer. *Laryngoscope, 117*, 238-241.
- Verdonck-de Leeuw, I. M., De Bree, R., Keizer, A. L., Houffelaar, T., Cuijpers, P., Van der Linden, M. H., & Leemans, C. R. (2009). Computerized prospective screening for high levels of emotional distress in head and neck cancer and referral rate to psychosocial care. *Oral Oncology, 45*, 129-133.
- Weis, J. (2003). Support groups for cancer patients. *Supportive Care in Cancer, 11*, 763-8.
- Zwahlen, D., Hagenbuch, N., Carley, M. I., Recklitis, C. J., & Buchi, S. (2008). Screening cancer patients' families with the distress thermometer (DT): a validation study. *Psychooncology, 17*, 959-966.

SANNE KRUL

Graduated as a psychologist and carried out this research at the Department of Clinical Psychology at the VU University in Amsterdam, the Netherlands.

MARJET DOCTER

Working as an advisor at the Comprehensive Cancer Centre the Netherlands. She advises and assists health institutions to improve quality of care, in particular implementation of screening for psychosocial care needs.

CHRISTINE BROUWER-DUDOK DEWIT

A clinical psychologist and family therapist who works with

families, couples and individuals confronted with cancer in her own practice. As a researcher she strongly believes that monitoring and reflecting upon the psychological care provided will enhance the quality of the care.

IRMA VERDONCK-DE LEEUW

Graduated as a psychologist, speech pathologist, and linguist. She is Professor at the Department of Clinical Psychology of VU University and at the Department of Otolaryngology – Head & Neck Surgery of VU University Medical Center (VUmc) / Cancer Center Amsterdam, in Amsterdam, the Netherlands. She holds the chair 'Living with Cancer: innovative care programs and e-health' established by the Dutch Cancer Society (KWF) / Alpe d'HuZes Foundation.