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Counselee participation in follow-up breast cancer genetic counselling visits and associations with achievement of the preferred role, cognitive outcomes, risk perception alignment and perceived personal control

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ABSTRACT

The purpose of the study was to assess the counselee participation in the follow-up visits, compared to the first visits, for breast cancer genetic counselling and to explore associations with counselees' achievement of their preferred role in decision making, information recall, knowledge, risk perception alignment and perceived personal control.

First and follow-up visits for breast cancer genetic counselling of 96 counselees of a Dutch genetics center were videotaped (2008–2010). Counselees completed questionnaires before counselling (T1), after the follow-up visit (T2) and one year after the follow-up visit (T3). Consultations were rated with the Roter Interaction Analysis System (RIAS). Counselee participation was measured as the percentage of counselee utterances, the percentage of counselee questions and the interactivity (number of turns per minute).

Follow-up visits had higher levels of counselee participation than first visits as assessed by the percentage of counselee talk, the interactivity and counselee questions. More counselee talk in the follow-up visit was related to higher achievement of the preferred role (T2) and higher perceived personal control (T3). Higher interactivity in the follow-up visit was related to lower achievement of the preferred role in decision making and lower information recall (T2). There were no significant associations with the percentage of

questions asked and none of the participation measures was related to knowledge, risk perception alignment and perceived personal control (T2).
In line with the interviewing admonishment 'talk less and listen more', the only assessment of counselee participation associated to better outcomes is the percentage of counselee talk. High interactivity might be associated with lower recall in breast cancer genetic counselees who are generally highly educated. However, this study was limited by a small sample size and a heterogeneous group of counselees. Research is needed on the interactions causing interactivity and its relationships with involvement in decision making and recall.

1. INTRODUCTION

Cancer genetic counselling aims to help counselees to make their own choices with regard to DNA-testing, periodic surveillance and informing relatives about their risks and to regain a sense of control (Resta et al., 2006). Several outcomes have been identified. Achievement of the preferred role in decision making is important for counselees to make their own decision (Wang et al., 2004). Counselees' information recall, knowledge of hereditary breast cancer and risk perception alignment are relevant to evaluate whether the counsellor's information was remembered, understood and whether it altered the counselee's feelings about her risk (Kasparian et al., 2007). Finally, the level of perceived personal control is assessed as an aim. While counselling has been shown to modestly improve breast cancer genetics knowledge (Meiser et al., 2001), it has little positive impact on counselees' risk perception alignment (Smerecnik et al., 2009 and Butow et al., 2003) and provides small increases in the sense of personal control (Pieterse et al., 2011). Therefore, new ways for improving the counselling process should be found.
Breast cancer genetic counselling usually consists of pre-test and post-test counselling, each dealt with in mostly one visit (Hopwood et al., 2003). The first visit focuses on the interpretation of personal and family cancer histories and education about hereditary breast cancer and DNA-testing. In the Netherlands, approximately two-third of the counselees receives an indication for DNA-testing for herself or an affected relative (Albada et al., 2012). Several months later, these counselees attend a follow-up visit. In this visit the counselee receives risk estimates and surveillance recommendations for herself and first degree relatives. Therefore, the follow-up visit is a crucial moment for achieving improved outcomes. However, most process studies have been restricted to the first visit and little is known about the follow-up visit for breast cancer genetic counselling (Meiser et al., 2008).
Based on evidence from neuropsychological studies, increased counselee participation might hold the key to improving outcomes. These studies indicate that to better retain information, it needs to be processed elaborately in the brain, i.e. one has to attach meaning to it (Sousa, 2006). More active participation, i.e. talking instead of only listening, activates more senses, increases elaborate processing and thereby enhances learning (Goswami, 2008). Better recall could thus be obtained by letting counselees discuss what the information means to them. Additionally, a consultation with higher interactivity contains shorter blocks of information which better fit the concentration span to be more easily processed and remembered (Sousa, 2006). Finally, counselee questions enable the counsellor to adjust information to the individual counselee, leading to more tailored and personalized information (Kelly et

al., 2005 and Van Dijk et al., 2005). People process personally tailored information more elaborately and it is therefore better remembered (Sousa, 2006). Literature thus indicates that more counselee participation could be related to improved knowledge and recall. In cancer care, patient question asking was also found to be related to increased recall of information, presumably because the questions enabled more tailored information giving by the health care provider (Van der Meulen et al., 2008). Additionally, higher levels of interactivity could create more opportunity for the counselee to express perceptions about risk and values concerning screening, necessary for involvement in decision making (Street et al., 2009). The counselee asking questions, sharing his/her view and providing information are important conditions for patient-centred communication, which is postulated to increase counselee's knowledge, shared understanding, the quality of decisions and self-management (Street et al., 2009).

Indeed, studies with simulated counselees indicate positive effects of counselee participation in the first visits, as more counselee talk was found to be associated with higher satisfaction (Meiser et al., 2008). Also, higher interactivity enabled low literate simulated counselees to learn and there was increased learning in consultations with more personalised information (Roter et al., 2009). However, previous studies focused on first visits for breast cancer genetic counselling, which are known for their low levels of counselee participation, as assessed by their percentage of talk, the interactivity and the number of counselee questions (Butow and Lobb, 2004, Ellington et al., 2005, Ellington et al., 2006, Lobb et al., 2001, Roter et al., 2009, Lobb et al., 2002, Lobb et al., 2004, Lobb et al., 2005, Meiser et al., 2008, Pieterse et al., 2005a and Pieterse et al., 2007). Also, findings with simulated counselees may not hold true in real consultations.

The current paper is the first to explore associations of counselee participation in the follow-up breast cancer genetic counselling consultation to counselee-reported outcomes. We will assess (1) the counselee participation in the follow-up consultation and compare this to the counselee participation in the first consultation, (2) the associations between counselee participation in the follow-up visit and counselees' achievement of their preferred role in decision making, information recall and knowledge, risk perception alignment and perceived personal control after the follow-up visit and one year after the (final) follow-up visit.

2. Methods

The present study was conducted as part of a larger study on breast cancer genetic counselling at the department of Medical Genetics of the University Medical Centre (UMC) Utrecht (Albada et al., 2012). The study was approved by the medical ethical committee of this hospital. Consecutive new counselees were included from February 2008 to April 2010. Counselees who were aged 18 years or older and were the first of their first degree family to seek breast cancer genetic counselling, were sent information about the study and an opt-out form including a question about reasons of withdrawal. Counselees were ineligible if they lacked internet or email access. At the start of the first consultation the counsellor collected the informed consent form. All 13 counsellors performing follow-up breast cancer genetic counselling consultations at the department participated and counselled 2 to 17 counselees each. Counsellors were clinical geneticists (n = 3), clinical geneticists in training (n = 4), genetic counsellors (n = 3) or genetic counsellors in training (n = 3).

Both first and follow-up consultations were videotaped and the camera was directed at the counsellor. 96 counselees had a follow-up consultation that was videotaped (Fig. 1). Nine counselees had a follow-up consultation that was not videotaped due to logistic failure. Of two counselees there was no videotape of the first consultation due to technical problems. One first consultation was only videotaped for the first half and one recording missed the first part of the consultation.

[FIGURE 1]

Six counselees had an intermediate follow-up consultation between the initial and the final follow-up consultation. Mostly this intermediate consultation was to clarify the family medical history. These intermediate consultations were not taken into account in this study.

Counselees completed a digital questionnaire before counselling (T1), approximately one week after the final follow-up visit (T2) and approximately one year after the final follow-up visit (T3). Counselees received a summary letter approximately one month after the final visit. Data were initially gathered for a randomized controlled trial of the effects of a pre-visit tailored website on genetic counselling outcomes for hereditary breast cancer in which participants were randomized to receive usual care or usual care plus an educational website. In the current study, this group allocation is controlled for.

2.1. Counselee characteristics

Age, having children, family cancer history and educational attainments were assessed in the baseline counselee questionnaire. All but the latter two were derived from the medical file if missing. Two missing values on education were imputed with the median. Counsellors estimated the risk for the counselee to develop breast cancer (again) with Claus tables and the Claus extended formula as integrated in the Dutch guidelines (Van Asperen et al., 2004). They completed this risk on a 0–100% visual analogue scale (VAS) in a questionnaire after the final visit. The risk was checked with the medical files and when revised due to e.g. changes in the family cancer history, we copied the risk from the medical file. For five affected counselees with an uninformative DNA-test result their risk was missing and was imputed with the mean risk for affected counselees who received an indication for testing and an uninformative test result. Breast cancer disease status, indication for DNA-testing and test results were derived from the medical file.

2.2. Questionnaires

The T1 questionnaire assessed the preferred level of involvement in decision-making and evaluated this role with items adapted for breast cancer genetic counselling from Gattellari et al., 2001 and Sutherland et al., 1989). The preference for involvement in decision making around DNA testing, adhering to surveillance recommendations and informing relatives about risks and surveillance, was assessed at T1 and T2. For the analyses we used the T2 assessment because the consultation itself can change the preference (Butow et al., 1997). Counselees were asked to select a response to a question assessing preferences: (1) the counsellor makes all decisions using all that he/she knows about genetic counselling; (2) the counsellor makes all decisions but strongly considers my opinion; (3) the counsellor and I make all decisions together; (4) I make all decisions but strongly consider the counsellor's opinion; 5) I make all decisions using all that I know and learn about genetic counselling. Counselees

evaluated their level of involvement in decision making by selecting one of the responses formulated in the past tense. Counselees were considered to have *achieved their preferred level of involvement* if they had given the same score to the preference and the evaluation.
Questionnaires included seven items to assess the level of accurate *knowledge about hereditary breast cancer* (Pieterse et al., 2005b). Respondents indicated whether each item was correct, incorrect, or whether they did not know. The knowledge score was the number of correct answers.
Counselees rated their perceived risk that they themselves would (re-)develop breast cancer in the future on a VAS (0–100%). *Risk perception* was defined as aligned if the counselee and counsellor estimates were within the same risk category, either population or slightly increased (<20%), moderate (20–30%) or high risk (≥30%) of developing breast cancer (again) (CBO, 2008). The surveillance recommendations are based on these risk categories (Van Dijk et al., 2004). The T4 questionnaire additionally assessed whether the counselee had risk reducing breast surgery.
The feeling of being in control (cognitive, behavioural and decisional) as related to the possibility of carrying hereditary breast cancer was assessed using the validated Dutch Perceived Personal Control questionnaire (Smets et al., 2006 and Pieterse et al., 2007). The score (mean of all 9 items) ranges from 0 to 2.

2.3. Information recall

Counselees' recall of information from the visit was assessed at T2 with seven multiple choice indications of whether a topic was discussed, e.g. limitations of DNA-testing and involving family members, with responses 1) no, not discussed, 2) yes it was discussed but I don't remember what was said, 3) yes, namely, with an invitation to write down what the counselee recalled (Jansen et al., 2008). Coders assessed whether the topic was discussed in the visit based on the videotape. Subsequently, items described were compared with the items mentioned by the counsellor (Jansen et al., 2008). If all items regarding a topic discussed were (correctly) described two points were given, if a part of the items was correctly described one point was given and if no items were correctly described no points were given. The percentage of accurate recall was calculated by dividing the sum of these points for all seven topics by the highest possible score based on the number of discussed topics. A second coder coded a random 10%. Interrater reliability (intra class correlation) was .94.

2.4. Coding of videotapes

Verbal communication was analysed with the Roter's Interaction Analysis System (RIAS) (Roter, 2006), adjusted for genetic counselling (Pieterse et al., 2005a). In the RIAS verbal dialogue is analyzed utterance by utterance, in mutually exclusive categories. An utterance is the smallest discriminable speech segment which expresses or implies a complete thought (Roter and Larson, 2002). We coded directly from the videotapes with the software program Observer XT7, allowing for analysis of the number and sequence of utterances (Noldus et al., 2000).
For the first consultation, we calculated the participation measures for the whole consultation and for the last part of the consultation, i.e. the whole consultation minus the first phase (until the family history was completed). The first phase of the first consultation mainly consist of assessing the personal and family cancer history (Butow and Lobb, 2004 and Pieterse et al., 2006). The remaining part mainly aims to

educate and counsel counselees (Resta et al., 2006) and might be more comparable to follow-up visits.

RIAS coding was conducted by five trained coders of whom two only coded first consultations and two others only coded final consultations. Reliability coefficients for categories with mean occurrence >2% were calculated (Roter, 2006). Interrater reliability was calculated between the three coders of the first consultations and between the three coders of the follow-up consultations on a random 7% of the consultations. The main coders of the first and follow-up visits recoded a random 10% of their consultations. The inter-coder reliability (intra class correlation, ICC) for the first visits averaged .92 (range .78–1) and intra-coder reliability averaged .88 (.58–.99). For the follow-up consultations inter-coder reliability coefficients averaged .86 (.39–.99). Intra-coder reliability coefficients averaged .96 (.75–1). The lowest values of the inter-coder reliability in the follow-up visits (.39 and .51) concerned the RIAS category agreement (implying agreement or acceptance, e.g. yes, indeed) for counsellors and counselees respectively. This category was hard to distinguish from the RIAS category backchannel responses (implying attentiveness, e.g. hmmm, yeah). We therefore lumped agreements and backchannels.

3. Participation measures

The percentage of counselee utterances and the number or percentage of questions are frequently used to assess counselee participation (Pieterse et al., 2005a, Epstein and Street, 2007 and Ellington et al., 2007). We calculated the counselee talk (utterances) and questions as a percentage of the total number of utterances in the consultation. Interactivity has been introduced as a new measure in simulated consultations (Roter et al., 2008 and Roter et al., 2007), but has not yet been assessed in routine consultations. The interactivity is the mean number of turns per minute between the counsellor (s) and the counselee (s). All shifts of floor are counted as a turn except for agreements and backchannels (Roter et al., 2008).

If two counsellors were present, their utterances were added. Similarly, if companions were present their utterances were added to those of the counselee (Pieterse et al., 2007). With regard to recall it has been found that the percentage of recall was not higher if a companion had been present during the consultation (Jansen et al., 2010).

4. Analysis

We compared the participation measures of the follow-up consultations with the first consultations with paired *t*-tests (two-sided significance testing). Additionally, we checked whether higher counselee participation in the follow-up consultation was associated with outcomes using multilevel regression analyses. A multilevel model was chosen because counselees were nested within counsellors. As the follow-up consultation was mostly (90 of 96) performed by the same counsellor as the first consultation the counselees were grouped based on the counsellor of their first consultation. The intra class correlation of the null model varied between 0 and 4.4% for the various outcomes. We applied multilevel analyses with random intercept at the counsellor level. Multilevel logistic regression analyses were performed for risk perception and achievement of the preferred level of involvement (xtlogit). For the other outcomes we used multilevel linear regression with maximum likelihood estimation (xtmixed, mle). We controlled for counselee age, education, disease

status, breast cancer risk and group allocation. For all analyses except for recall, we additionally controlled for baseline values. The AIC (Akaike Information Criterion) was used to assess the model fit for the basic model (model 1) and the model including the control variables (model 2). Analysed were conducted using Stata 12.

5. RESULTS

5.1. Counselee characteristics

The mean age was 44.1 and 40% of the counselees was highly educated (Table 1). For 69 counselees a DNA-test was performed for themselves or for an affected relative. For breast cancer affected counselees there was more often a DNA-test performed than for unaffected counselees who mostly had to request their relative to perform the DNA-test (Chi = 13.05; P = .000). If the relative did not agree with the DNA test, or has deceased, no DNA-test was performed. In such a case the risk estimate and surveillance recommendations were based on the medical family history as discussed in the follow-up consultation. Post-counselling the preference for involvement in decision making was significantly higher compared to pre-counselling (Chi^2 = 9.68; P = .046). Four counselees had risk reducing breast surgery at T4. Two of these counselees underestimated their risk, however, this may be due to their lowered risk after the risk reducing breast surgery.

[TABLE 1]

5.2. Breast cancer genetic counselling outcomes

Counselees correctly recalled less than half of the information items discussed in the follow-up visit (Table 2). Almost three quarters of the counselees (72%) achieved their preferred role in decision making. Scores for knowledge and perceived personal control were significantly higher post-counselling and one year post-counselling, compared to pre-counselling. The percentage of counselees who had an accurate risk perception was significantly higher at post-counselling compared to pre-counselling, but not at one year post-counselling compared to pre-counselling.

[TABLE 2]

5.3. Counselee participation in the follow-up compared to the first visits

Counselees participated significantly more in the follow-up compared to the first visits as measured by the percentage of counselee utterances, the interactivity and the percentage of counselee questions (N = 94; Table 3). No significant differences in the participation measures were found between breast cancer affected and breast cancer unaffected counselees.

[TABLE 3]

5.4. Associations between counselee participation and outcomes of the follow-up visit

The percentage of counselee utterances in the follow-up consultation was positively related to counselees' achievement of their preferred role in decision making (β = .60, p = .048; Table 4). The interactivity, i.e. number of turns per minute, was negatively related to the achievement of the preferred role in decision making (β = −.79; p = .01) and to the percentage of information recalled (β = −.29; p = .01). The percentage

of counselee utterances was positively related to perceived personal control one year after the follow-up visit (β = .19; p = .04), while there was no significant association with information recall. The percentage of counselee questions was not significantly associated with any of the outcomes.

[TABLE 4]

5.5. Sensitivity analyses

Several sensitivity analyses were performed. First, we performed the multilevel regression analyses with the counselees grouped per counsellor of the follow-up visit instead of the first visit and changes in results did not cross significance thresholds. Second, we performed the multilevel regression analyses with the control variable of education replaced by whether a DNA-test was performed or not. Third, we performed these analyses with education replaced by whether there was an uninformative test result or not. For both the second and third type of sensitivity analyses the association between the percentage of counselee utterances and achievement of the preferred involvement in decision making was not significant any more. Other results did not change. Fourth, we conducted the analyses without the six counselees who had seen a different counsellor at their follow-up compared to their first visit. The association between interactivity, achievement of preferred role and recall remained significant. The association between the percentage of counselee utterances with perceived personal control one year after counselling was B = .19 (P = .051) and with achievement of the preferred role was B = .62 (P = .05). However, withouth these six counselees power was further limited with 9 independent variables and 78 respondents and we therefore chose to report the analyses with these six counselees included.

6. DISCUSSION

This paper firstly aimed to compare the counselee participation in the follow-up breast cancer genetic counselling visits with the first visits. These first visits have been described as educational with little counselee participation. The current study shows that this characterisation does not hold true to the same extent for the follow-up visits as these contain significantly higher percentages of counselee talk, higher interactivity, and higher percentages of counselee questions than the first visits. Interestingly, a study of genetic counselling for pre-symptomatic testing in the USA showed a low percentage of counselee talk in both the follow-up and first consultations (Ellington et al., 2007). However, in that study counselling about emotional consequences and informing relatives was given after the follow-up visit and this might distort the comparison. Our study shows that with counselees who are the first in their family to request counselling, follow-up visits involve counselees more than the first visits.

Furthermore, this paper explored associations of counselee participation with genetic counselling outcomes. A higher percentage of counselee talk was associated with more achievement of the preferred role in decision making. Generally, counselees preferred more involvement in decision making than experienced. Apparently, when counselees talk more, they perceive more involvement in decision making, or vice versa, when they feel more involved in decision making they talk more. As their preferences for involvement were higher post-counselling than pre-counselling,

counselees may need explicit invitations for involvement in decision making. The percentage of counselee talk was not significantly associated to recall and knowledge. In the follow-up visit the personal risk estimation and surveillance recommendations are conveyed and this information is highly personally relevant. Therefore, information in the follow-up visit might be processed elaborately regardless of the percentage of counselee talk. Furthermore, counselee participation was unrelated to risk perception alignment. The counselees' risk perception was more in line with the risk estimate post-counselling compared to pre-counselling, but many counselees still overestimated their risk. Due to the anchoring-and-adjust bias (counselees may adjust their perceived risk toward- but not equal to- the risk estimate provided) a completely correct perception may not be achievable (Linnenbringer et al., 2010). Given the lower risk perception alignment at one year follow-up compared to post counselling, the risk perception might further drift away from the risk estimate over time. Studies with shorter (six months) follow-up periods did not find significant deterioration (Pieterse et al., 2011 and Van Dijk et al., 2005).

Consistent with our expectation, counselee talk was positively associated with perceived personal control one year after the visit. This did not seem to be related to higher scores for the perceived participation in decision making (post hoc analysis, r = .02). Instead, it might be related to a heightened needs fulfillment after counselling due to the higher percentage of counselee talk, as was shown in a previous study (Dijkstra et al., 2013). Possibly, talking more in the follow-up visit could enable counselees to think about decisions and to behave according to their preferences, in other words, to gain a higher level of perceived personal control. Alternatively, those experiencing more control one year post-counselling might have been more in control during the consultation due to personal characteristics not included in this study.

The association of interactivity with both the achievement of the preferred role in decision making and information recall was unexpectedly negative. Several explanations are possible. Firstly, this was the first study to assess interactivity in real consultations, as opposed to simulated consultations (Roter et al., 2007, Roter et al., 2008 and Roter et al., 2009). In real consultations interactivity might not only be caused by shorter blocks of information, paraphrases and checks for understanding, which usually indicate good alignment between conversational partners (Roter, 2006). Higher rates of interactivity might also be due to lack of structure of the counsellor's information, repeated interruptions by counselees as a previous question was still unanswered and by poor listening of counsellors, which usually indicate a lack of alignment (Roter, 2006). This is to be assessed by future studies.

Furthermore, a post hoc analysis showed that high rates of interactivity were associated to higher percentages of social talk (small talk) (r = .49; P = .00). Whereas social talk is important to make the counselee feel at ease, it is unclear how these utterances are relevant for feelings of being involved in decision making. Future research should therefore focus on the type of interactions causing high interactivity and the associations of each of these with visit outcomes.

Secondly, counselees may gain from interactivity up to a certain level. A study with simulated first visits in the USA showed a low mean interactivity rate (2.3) (Roter et al., 2007) compared to ‘real-life’ first visits (5.6) in the current study. Unfortunately, we could not test whether there was a reverse U-curve relation as the lowest interactivity in this study was relatively high (2.97).

Thirdly, our finding may be explained by the high educational level of the counselees. The study of Roter et al. (2009) found that more interactive first visits resulted in more learning of low literate simulated counselees and found a trend for less learning of high literate simulated counselees. The authors postulate that higher interactivity compromises organized and comprehensive organization of information, which may hamper learning for those high literate, used to process large amounts of information. The current study sample was highly educated with only 2% of counselees not having finished high school, i.e. below 8th grade of education. This high educational level is representative for Dutch counselees and comparable to educational levels reported in the UK (Metcalfe et al., 2007), USA (Ellington et al., 2005) and Australia (Butow et al., 2003). For these highly educated counseleeslow levels of interactivity might not be a problem as they are able to grasp dense information. Future studies should clarify whether the optimal rate of interactivity differs for high versus lower educated counselees.

The current study adds to the discussion about how to capture counselee participation. In line with the interviewing admonishment ‘talk less and listen more’, the measure of counselee participation related to better outcomes was the percentage of counselee talk. As previous studies have also found significant associations with the percentage of counselee talk (Dijkstra et al., 2013 and Epstein and Street, 2007) we think that it can be considered an important indicator for participation. However, it is unknown how much speaking time counselees need to present their concerns, discuss their views and participate in decision making. For instance, a study of Langewitz et al. (2002) found that 2 min of uninterrupted patient speaking time at the start of the consultation was enough for patients to present their problem and determine the agenda. Future research might thus focus on the timing of counselee talk.

Furthermore, Roter et al. (2008) introduced interactivity as a new measure of patient participation that might be related to patient centred communication and better outcomes. However, the current study with real consultations suggests that higher interactivity might be negatively associated with recall and achievement of their preferred role in decision making in a population of highly educated counselees in breast cancer genetic counselling. Future research should assess whether frequent turn taking helps counselees to feel heard and understood. Surprisingly, the percentage of counselee questions was not significantly related to any of the outcomes and this might challenge its relevance. Asking questions was not hypothesized to have a direct beneficial effect on outcomes, but rather through receiving more personally relevant information. However, some variation in the percentage of questions might be explained by responsiveness to the counsellor, i.e. asking more questions when little personally relevant information is given and asking few questions if a lot of personally relevant information is given. When counsellors are responsive to the counselee's needs, the counselee would not need to ask questions and a significant association is not to be found (Stiles, 1989). This would be in line with results of Pieterse et al. (2007) indicating a negative association between the number of questions and counselee satisfaction with first consultations. Associational studies are not sensitive for this responsiveness and qualitative studies are needed to better grasp the level rapport.

7. Methodological reflection

There are several strengths and limitations to this study. First, we corrected for the nesting of counselees within counsellors with multilevel regression. Hereby, we overcame a drawback of some prior studies on communication and outcomes in genetic counselling (Meiser et al., 2008). However, the number of 13 counsellors limited the power. Therefore, counsellor characteristics, such as gender and age, could not be involved in the analyses. Second, when the data for the study was collected the waiting time for DNA-test results was three to six months and this has recently been reduced to two months. Future studies should show whether this shortened time between the first and follow-up consultation will bring about changes in counselees' well-being, such as perceived personal control. Third, for the analyses we used counselees' preference for involvement in decision making from the post-visit questionnaire because these were higher than the pre-counselling preferences. No measurement shortly (<4–6 months) prior to the follow-up consultation was available and preferences are subject to change over time (Butow et al., 1997). Fourth, we choose to analyse communication with RIAS. While this instrument is very valuable for assessing the structure of a consultation, it does not provide in-depth information about the content of the visit (Sandvik et al., 2002). Therefore, we could not determine whether questions were answered appropriately and whether information was understandable. Future qualitative studies are needed to address these questions. Fifth, due to the exclusion criteria of having internet or email access, 24 (5.6%) of the counselees who were sent study information were excluded and this might have biased results. Finally, this study did not involve the surveillance adherence. Future long term research should evaluate the communication in genetic counselling with regard to adherence. However, counselees' involvement in decision making, i.e. making their own decision, is recently being recognized as an important outcome, regardless of adherence (Resta et al., 2006). Finally, while the heterogeneous group of counselees in this study reflects the practice of breast cancer genetic counselling, the heterogeneity and small sample size limit the statistical power. Preventive options and informing of relatives are different for counselees with or without an indication for DNA-testing and for those with an uninformative versus a BRCA1/2 test result. Nonetheless, it is important to report about the follow-up visits for breast cancer genetic counselling while including all these counselees.

8. Practice implications

The results of this study support the advice for genetic counsellors to ‘talk less and listen more’. To feel more involved in decisions and regain a sense of personal control counselees could be explicitly invited to talk about their perceptions of their risk and their surveillance options (Van Dijk et al., 2004, Pieterse et al., 2006, Michie et al., 2003 and Vos et al., 2011).

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FIGURES AND TABLES

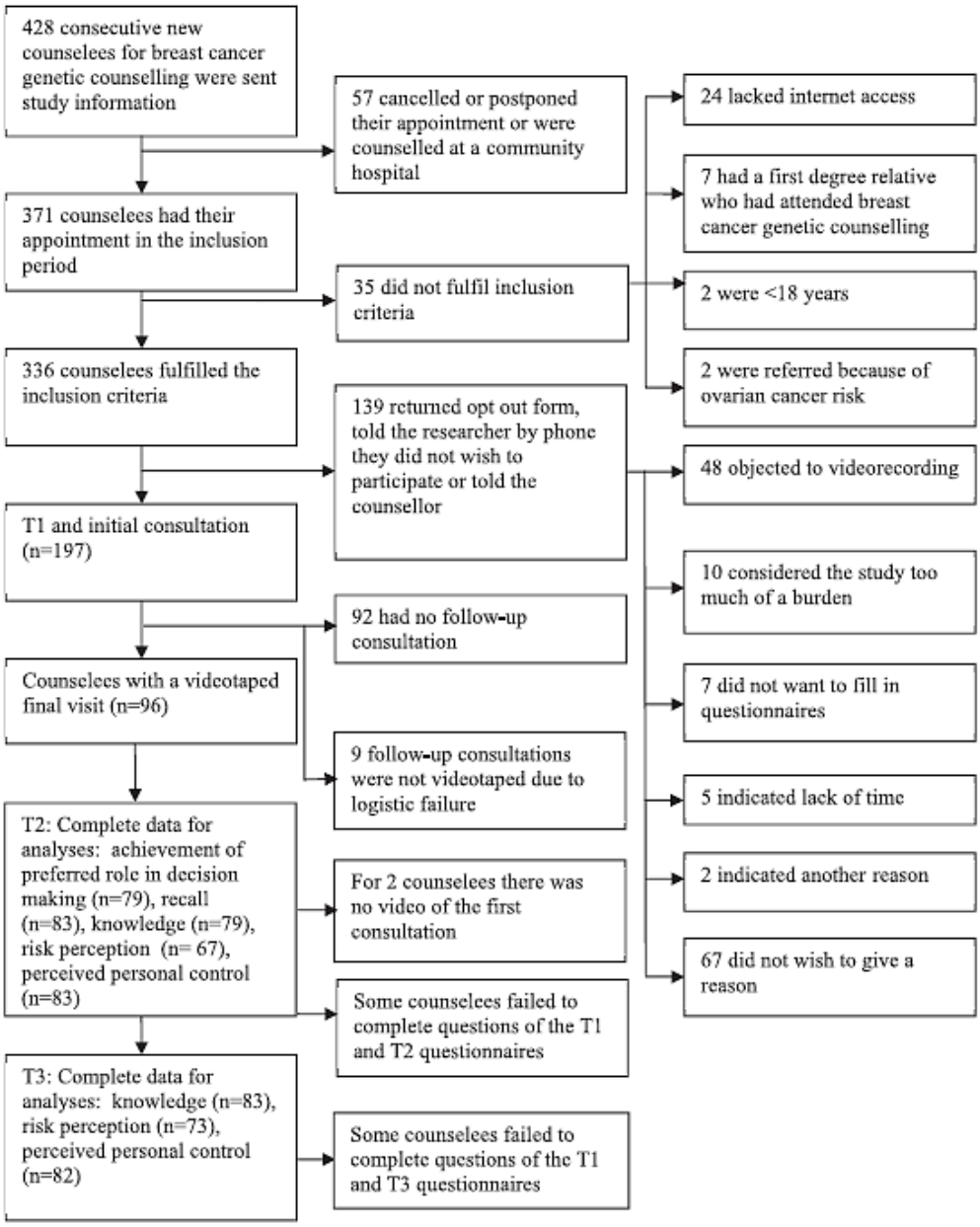

Fig. 1. Study procedure.

Table 1. Counselee characteristics (*N* = 96).

	n	%	Range	Mean (SD)
Age (years)	–	–	21–69	44.1 (12.2)
Children (having children)	73	76.0	–	–
Educations [a]				

	n	%	Range	Mean (SD)
<High school level	2	2.1		
High school/Secondary education	26	27.7		
Middle vocational education	28	29.8		
University (MSc/BSc)/higher vocational education (BSc)	38	40.4		
Breast cancer (affected)	64	66.7	–	–
Indication for DNA-testing for counselee or affected relative	89	92.7		
DNA-test uptake	78	81.3		
BRCA1/2-test result [b]				
Uninformative test result	65	67.7	–	–
BRCA1/2 mutation carrier	7	7.3		
50% risk of being a BRCA1/2 mutation carrier[c]	1	1.0		
Variant of unknown clinical significance (VUCS)	6	6.3		
Breast cancer risk category [d]				
Population (<20% lifetime risk)	51	53.1		
Moderate (20–30% lifetime risk)	29	30.2		
High (≥30% lifetime risk)	16	16.7		

	Pre-counselling (T1)		Post counselling (T2)	
Preferred level of involvement in decision making				
Counselor making decisions (1,2)	6	6.4	9	11.4
Shared decision making (3)	43	45.7	28	35.4
Counselee making decisions (4,5)	45	47.9	42	53.2
Evaluation of involvement in decision making				
Counselor made decisions (1,2)			18	22.8
Shared decision making (3)			27	34.2
Counselee made decisions (4,5)			34	43.0

a. 2 missing values.
b. The total number of test-results counts 79 instead of the 78 counselees with test uptake as one test result indicated a BRCA1/2-mutation as well as a VUCS.
c. Breast cancer unaffected counselees with a first degree relative who tested positive for a BRCA1/2 mutation.
d. The lifetime risk of developing breast cancer (again) for the counselee as estimated by the counsellor at T2.

Table 2. Counselees' mean level of information recall, knowledge, perceived personal control, the percentage of counselees who achieved their preferred role in decision making and the percentage of counselees with an accurate risk perception.

	Pre counselling (T1)		Post counselling (T2)		One year post counselling (T3)	
	M	SD	*M*	SD	*M*	SD
Recall (0–100%)	–	–	40.4	22.1	–	–
Knowledge of breast cancer and heredity (0–7)	4.60	1.50	6.11***	1.07	6.00***	1.04
Perceived personal control (0–2)	1.16	.39	1.31**	.50	1.37***	.49

	N	%	*N*	%	*N*	%
Achieved preferred role in decision making	–	–	57	72.2	–	–
Accurate risk perception	24	29.3	37	48.7*	32	38.1##

Statistical significances (two-sided *t*-tests and Chi2).
Difference with the pre-counselling value *$P < .05$, **$P < .01$, ***$P < .001$.
Difference between the post-counselling and one-year post counselling value $^{\#\#}P < .01$.

Table 3. Visit characteristics of the follow-up consultations compared with the first consultations.

	First consultation (*n* = 94)	First consultation without family history phase (*N* = 93)	Follow-up consultation (*N* = 94)
	M (SD)	*M* (SD)	*M* (SD)
Percentage of counselee utterances	44.27 (5.72)***	40.18 (7.59)***	48.14 (5.97)
Interactivity	5.57 (1.52)*	4.45 (1.55)***	6.05 (1.72)
Counselee questions as percentage of all utterances	1.45 (1.05)**	1.84 (1.30)	2.08 (1.32)
Duration (min)	49.88 (15.83)***	37.53 (14.20)***	23.73 (14.47)

Statistical significance (two-sided) of the difference with the follow-up consultation (*t*-tests).
*$P < .05$.
**$P < .01$.
***$P < .001$.

Table 4. Associations of counselee participation in the follow-up breast cancer genetic counselling visit with outcomes; Beta's and standard errors from multilevel regression analyses.

	Achievement preferred role	Recall	Knowledge		Risk perception alignment		Personal perceived control	
	T2 (*n* = 79)	T2 (*n* = 83)	T2 (*n* = 79)	T3 (*n* = 83)	T2 (*n* = 67)	T3 (*n* = 73)	T2 (*n* = 83)	T3 (*n* = 82)
	B se	B se	B se	B se	B se	B se	B se	B se
Model 1								
Baseline value	–	–	.29** (.10)	.43*** (.11)	1.46* (.61)	.38 (.55)	.41*** (.10)	.43*** (.10)
Percentage of counselee utterances	.59* (30)	−.03 (.11)	.17 (.10)	.06 (.10)	.25 (.25)	−.24 (.25)	.11 (.10)	.18 (.10)
Interactivity	−.58* (.27)	−.28** (.11)	−.20 (.10)	.10 (.10)	.06 (.27)	−.03 (.26)	−.11 (.10)	−.06 (.10)
Counselee questions as percentage of all utterances	−.11 (.28)	.06 (.11)	.13 (.11)	.08 (.10)	−.04 (.29)	−.46 (.28)	.17* (.07)	−.04 (.07)
AIC	96	239	222	233	97	106	224	223
Model 2[a]								
Age			−.22* (.11)	−.28** (.10)				
Education (MSc/BSc. vs. low)		.44* (22)						
Breast cancer affected								
Risk of breast cancer			.22* (.11)				.22* (.10)	
Group allocation								
Baseline value	–	–	.25** (.10)	.35** (.11)			.42*** (.10)	.46*** (.10)
Percentage of counselee utterances	.60* (.30)	−.04 (.11)	.17 (.10)	.07 (.10)	.36 (.28)	−.31 (.27)	.11 (.09)	.19* (.09)

	Achievement preferred role	Recall	Knowledge		Risk perception alignment		Personal perceived control	
	T2 (*n* = 79)	T2 (*n* = 83)	T2 (*n* = 79)	T3 (*n* = 83)	T2 (*n* = 67)	T3 (*n* = 73)	T2 (*n* = 83)	T3 (*n* = 82)
	B se	B se	B se	B se	B se	B se	B se	B se
Interactivity	−.79* (32)	−.29* (.11)	−.16 (.11)	.13 (.11)	.27 (.30)	−.15 (.28)	−.04 (.10)	−.02 (.10)
Counselee questions as percentage of all utterances	−.01 (.31)	.01 (.12)	.01 (.11)	−.03 (.11)	−.13 (.34)	−.43 (.33)	.13 (.08)	−.09 (.10)
AIC	105	244	221	234	100	110	228	225

***$P < .001$; **$P < .01$; *$P < .05$.

a. Only Beta's of control variables reaching statistical significance are shown.