Shared decision making and the use of outcome information in decisions about post-treatment surveillance after breast cancer treatment – Analysis of quantitative data

Health psychology and technology

Bachelor thesis

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Abstract

Background: Shared decision making (SDM) is suggested as the preferred approach when it comes to post treatment surveillance of breast cancer patients. The current high surveillance schedule might not be necessary for all patients and is rather a preference-based decision. However, it is still not the main approach when it comes to post treatment surveillance of breast cancer patients. Accordingly, the aim of this study was to examine the extent to which SDM currently takes place among post-treatment breast cancer patients. Factors that might influence patients' perception to which extent SDM currently takes place, are the patient's age, and health literacy. Hence, this study aims at identifying associations between SDM, age and health literacy, as well as to examine if the relationship between age and shared decision making is moderated by health literacy. **Methods:** A cross-sectional design was adopted. The sample was composed of 266 female post-treatment breast cancer patients. The variable SDM was assessed with the SDM Q-9 and the CollaboRATE (Barr et al., 2014; Kriston et al., 2010). Further, health literacy was assessed through the SBSQ (Fransen et al., 2011). A Pearson correlation has been calculated for the variables SDM, age and health literacy. A multiple linear regression was conducted in order to reveal a possible moderation effect of the variable health literacy on the independent variable age and the dependent variable SDM.

Results: In the post-treatment phase, SDM currently takes place occasionally. Older age was weakly associated with higher SDM (SDM Q-9) (r=0.21 ,p<0.05), but no association between age and CollaboRate was found. Moreover, health literacy and SDM (SDM Q-9) were weakly negatively associated with each other (r=-0.15, p<0.05). However, no association between health literacy and SDM measured using the CollaboRATE could be found. Moreover, the instruments SDM Q-9 and CollaboRATE were found to be strongly associated with each other (r = 0.73, p<0.01). Additionally, a negative weak correlation between age and health literacy was found (r=-0.15, p<0.05). The CollaboRATE did not show any significant

correlations besides with SDM Q-9. Additionally, no moderating effect of health literacy on age and shared decision making was found.

Discussion: The results of this study were to   some extent in line with previous findings of other studies which associated age and health literacy with shared decision making   . Future research should aim to further investigate breast cancer post treatment surveillance to find further factors that influence the extent of perceived SDM among patients. This is important because the current extent of SDM taking place can be significantly improved.

Introduction

Breast cancer is one of the most frequently diagnosed life threatening illnesses within our modern society   ,   with more than 1.5 million   diagnoses among women worldwide (de Ligt et al., 2019; Sun, et al., 2017; Sharma et al., 2010). According to the study by Momenimovahed & Salehiniya (2019), the incidence rate of breast cancer is rising to reach 3.2 million cases worldwide by 2050.   This strong increase is also experienced in the Netherlands, as statistics display an increase in the lifetime danger of developing cancer of 1 in 9.3 women in 1990 (10.8%) and 1 of 6.6 women in 2010 (15.2%) (van Der Waal et al., 2015). Despite the alarming growth in incidence rates, breast cancer mortality rates within the Netherlands seem to be decreasing. According to van Der Waal et al. (2015), who compared breast cancer mortality rates of 1990, 2000, and 2010, a steady but continuous reduction can be observed (4.5% deaths caused by breast cancer in 1990, and only 3.7% in 2010).   This shows that even though the breast cancer incidence rates are rising, the mortality rates are declining. More and more women become breast cancer survivors and are receiving follow up care (van Der Waal et al., 2015).

Follow-up care

Follow-   up care for breast cancer consists of surveillance and aftercare. Surveillance is aimed at early detection of locoregional recurrences of breast cancer as well as detection of new primary breast tumours. The purpose of aftercare, on the other hand, is to evaluate applied therapy options of both, primary and adjuvant therapies, as well as screening for corresponding co-morbidities   and/or psychosocial complaints (Collins et al., 2004; Lafranconi et al., 2017).

Currently the post-treatment surveillance is one size fits all   The Dutch guidelines for post-treatment surveillance of breast cancer patients propose that patients are followed for at least 5 years after they received treatment, consisting of an annual mammogram for a period

of 5 years after treatment (Cardoso et al., 2019). This means that the post-treatment surveillance procedure is the same for all patients with no regards to individual risk factors, needs and preferences of the breast cancer patient. However, for many patients, this high surveillance schedule might not be necessary (Lafranconi et al., 2017). Therefore, research suggests that a more personalized approach, based on personal risk calculation may be favourable, which, in turn, leads to the number of mammograms being a preference-based decision (Onega et al., 2014). The national guidelines of the Netherlands suggest post treatment surveillance   that is personalized to each individual breast cancer patient as well, but it does not suggest options on how to implement it (Witteveen et al., 2015).

Shared decision making

One way to personalize surveillance   is the process of shared decision-making (SDM). SDM can be described as an approach that bases the decision-making process on the patients, needs, values and wishes, as well as on the most promising medical evidence in regards to success (de Ligt, et al., 2019). That is why SDM is considered as the optimal model taking into account both, patient preferences as well as patient involvement (Simmons et al., 2010). Within SDM it is common to make use of patient decision aids (PtDA). PtDA's have shown to be really effective in regards to decisional conflict reduction, increasing patients' knowledge, as well as reducing the ratio of patients who are rather indecisive as well as passive within their decision making (Simmons et al., 2010).   SDM has been shown to have a number of benefits. According to Spronk et al., (2018), SDM is associated with positive results in regards to the management of breast cancer. A study conducted by Joosten et al. (2008), concluded that patients' overall satisfaction increases when taking part in SDM. Additionally, the patients' confidence in the decision that has been made rises (Hauser et al., 2015). Another benefit of patients taking part in SDM is that it increases the overall life expectancy of that patient, as it decreases the morbidity of the consequences of hypertension (Frosch & Kaplan, 1999).   Further, the relationship between the patient and the health care professional improves (Frosch & Kaplan, 1999). Other advantages encompass improvements in treatment adherence, biomedical outcomes, as well as lower levels of concern regarding their disease (Adams & Drake, 2006; Frosch & Kaplan, 1999). Also, a symptom related advantage was able to be identified. According to Adams & Drake (2006), SDM can also account for decreased symptom burden.

However, SDM also comes with some disadvantages that need to be taken into account. If a patient has multiple choices, it "can increase the sense of lost opportunities, which in turn

will lead the patient eventually to experience feelings of regret" (Adams & Drake, 2006, p. 91). The more choices the patient has, the more likely it is for them to experience those feelings of regret. Another disadvantage is that the process of SDM is more time consuming for the healthcare professional, than eg. the paternalistic model. This results in SDM being the more expensive alternative (Gaston & Mitchell, 2005). Nevertheless, SDM still has areas that need some further investigation. Especially within the phase of post-treatment surveillance of breast cancer patients, not much is known about the extent to which the decision is currently made in SDM and which factors influence this extent. Therefore, it is important to gain insights in the factors that influence SDM in order to find solutions on how to increase the extent to which SDM is taking place. Another reason for the importance of gaining insights into the factors that influence SDM is that chronic and severe diseases can have a serious impact on the patients quality of life, due to the long term situation of those diseases (Müller-Engelmann et al., 2011). For such diseases long term compliance is often really important, which patients stated to be mainly a decision based on subjective values, as patients might stop complying when they did not agree to the chosen treatment option. Hence, SDM is especially important for patients with chronic and severe illnesses (Müller-Engelmann et al., 2011).

Age

One factor influencing SDM is considered to be the patient's age. According to Schneider et al. (2006), the age of the participant can play a significant role in their preference of taking part in the decision-making process. Apparently, age can influence the interest of involvement in regards to health-related decisions. Similar results were detected according to another study. Here, the findings showed that the older population experiences greater barriers to being involved in shared decision making (Baker et al., 2000). This is also in accordance with the results of Gunn et al. (2015), who found a significant effect of age on shared decision making. Increasing age was linked with a decreasing preference for being involved in the decision-making process. Consequently, SDM is considered to be more attractive for younger (but also better-educated) patients (Frosch, & Kaplan, 1999). However, according to prior studies, it is possible that age might not single-handedly influence the patient's preference for involvement in the decision-making process. According to Amalraj et al. (2009), increasing age is associated with a decreasing health literacy. This, in turn, can influence patients to be less inclined in taking part in the decision-making process, due to age-related deficiencies in understanding health-related information (Amalraj et al., 2009).

Health literacy

Health literacy can be described as the skill to process and understand health-related information in order to make adequate health-related decisions (Stacey et al., 2017). The European Health Literacy Consortium defined health literacy as the person's ability to understand, process, access and apply health-related information in order to make corresponding appropriate decisions in regards to different domains of healthcare, namely illness prevention, and health promotion for being able to sustain or enhance their quality of life (Sørensen et al., 2013; Shen et al., 2019). Nevertheless, the definitions and conceptualizations of health literacy differ, making it difficult to narrow it down to one specific generalizable definition (Sorensen et al., 2012). However, health literacy seems to be associated with SDM according to Kim et al. (2001). Health literacy can possibly limit or enhance the participant's preference of taking part in SDM, depending on the extent of health literacy (Kim et al., 2001). Even though prior studies have examined the relation between health literacy and SDM, not much is known about the extent to which health literacy plays a role in SDM within the post-treatment surveillance phase of breast cancer patients. Aditionally, as mentioned in the age section, health literacy is associated with age (Galesic, & Garcia-Retamero, 2011). The findings of Baker et al. (2000) displayed that the older population showed a significantly lower health literacy. Findings of Amalraj et al. (2009), confirmed the results of Baker et al. (2000) and added some speculation about the relationship of age, health literacy and shared decision making. According to Amalraj et al. (2009), an increasing age is associated with a decreasing health literacy, which in turn can alter the relationship between age and health related decision making. Pelikan et al. (2018), specified the relationship of age and health literacy. They detected health literacy to be moderating the relationship between age and the patients' health. Interestingly, another study found age to be moderating the effects of health literacy on medication compliance. Due to age and health literacy often being linked as intervening variables in previous studies, this study will also examine whether health literacy serves as a moderator of age.

As only little is known about the extent of shared decision-making taking place in the post treatment surveillance phase, this study will focus on the relationship between age, health literacy, and shared decision making of breast cancer patients who are (at the point of the data collection) in the post treatment surveillance phase. An additional focus point of this study will be whether the relationship between age and SDM is influenced by health literacy in the post treatment surveillance phase since prior research is lacking in that area of research.

On the basis of that the following research questions are formulated:

RQ1: To what extent is the decision about post-treatment surveillance currently a shared decision?

RQ2: To what extent are the patient's age and health literacy level associated with SDM?

RQ3: Is the relationship between age and Shared decision making moderated by Health Literacy?

Methods

Design

For this scientific paper, secondary data was used. The data was collected in the year 2020, as a part of the PhD study of Jet Ankersmid, and consists of the baseline data of a Multiple Interrupted Time Series (mITS) study. The current study scrutinized the research questions on the pre-implementation data (baseline data) only. A cross sectional design was selected to investigate the influence of the variables age, and health literacy, on SDM.

Participants and Procedure

The Ethical approval for this scientific research was done in accordance with the declaration of Helsinki (World Medical Association, 2001). In order to be eligible to participate in the study, participants had to fulfil the following inclusion criteria: The potential participant must 1. face the decision for organizing follow-up care after having received curative treatment for invasive breast cancer, 2. have access to and experience in using a PC, laptop, tablet or smartphone with an internet connection (if needed, caregivers can assist the patient), 3. be treated in one of the Santeon hospitals[1], 4. understand the Dutch language in speaking and writing and are able to give informed consent. Exclusion criteria were: 1. being diagnosed with non-invasive breast cancer, 2. receiving palliative treatment or neoadjuvant therapy, 3. being male, 4. being incapable of completing the questionnaire, even with help from a family member or caregiver. All potential participants were invited by the healthcare professionals of the Santeon hospitals, who were asked to screen all patients to find out which patients meet the inclusion criteria and are therefore eligible to participate in the study. Therefore, the sampling method used for the recruitment of participants was consecutive sampling.

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[1] Santeon hospitals are a group of seven teaching hospitals in the Netherlands

All potential participants that were interested in taking part in the study received the patient information letter as well as the informed consent. The signed informed consents were stored in the treating Santeon hospital. The participants were asked to fill out the digital questionnaire to their most honest extent, as the questions addressed the participants perceived experience in consultation and other post-treatment care related matters. However, if patients had trouble filling out the questionnaire, they were allowed to get assisted by their caregiver. The sample size of the data set consisted of 266 women who suffered from breast cancer and were at the time the data was collected at the (1 year) post treatment stage. However, since 14 participants did not fill out the survey, the data of only 552 participants were analysed for the demographics. For SDM only data 249 participants were examined, as some participants did not fill in the entire survey.

Instrument

Personal background variables

The variable *age* was assessed by asking participants to indicate their age by the year they were born in.

The patient's *marital status* was assessed by giving the patients five options from which they could choose from, namely if they were 'widowed (=1)' 'divorced (=2)', 'single (=3)', 'living together/married (=5)',   , and 'other'. In case participants selected the answer option 'other', they had the chance to specify with their own words what type of marital status they are engaged in. These answers were then assigned to the other categories and   the category 'in a relationship (= 4)' was added.

The participant's occupation was also assessed by asking participants about their daily activities and reduced into two categories: .   1 = 'having a paid job' (being paid for … hours per week) and 2 =   'not having a paid job' (encompassing 'WAO/disabled', 'AOW/VUT/ pension', 'voluntary/ unpaid job', 'household tasks', 'studying/training'). The concrete answers from the option 'different' were assigned to the other categories.

For the variable *education*, the patient was asked to indicate their highest completed level of education by selecting one out of 9 options.   The answers were grouped into three categories: 1= 'Low' ('no education', 'primary education' and 'primary or preparatory vocational education'), 2= 'Middle' ('secondary general education', 'secondary vocational education and vocational guidance', 'higher general and preparatory scientific education'), and 3= 'High' ('higher vocational education', and 'scientific education').

In order to assess the variable 'health literacy', the **Set of Brief Screening Questions (SBSQ) (Fransen et al., 2011; Vreugdenhil et al., 2018)** was selected and used. The SBSQ measures the extent to which a patient is able to process and understand health related information in order to make adequate health decisions. It is a 3-item questionnaire, with each question being answered on a five-point Likert scale. The first and third item of the questionnaire have equal answering options, ranging from 'Never' to 'Always'. The second item has unlike the other two items different answering options, despite being answered on a five-point Likert scale as well. The exact wording of the second item is 'How confident are you that you are able to fill out medical forms correctly by yourself?'. Here, the answering categories were 'Not sure at all', 'A little bit sure', 'A bit sure', 'Quite sure', and 'Very sure'. Furthermore, the SBSQ demonstrated acceptable psychometric properties, with a Cronbach's alpha coefficient of 0.69, indicating solid internal consistency (Fransen et al., 2011). The computed cronbach's alpha coefficient for this exact sample showed a lower reliability of 0.54. Improving the Cronbach's alpha coefficient by eliminating one item did not work. Hence, despite this low Cronbach's alpha coefficient, it was decided to combine the items into a scale score, since the scale has been proven reliable in a number of prior studies (Fransen et al., 2011; Vreugdenhil et al., 2018). In order to calculate the scale score of each patient, all three items were added up and then averaged. The interpretation of the was evaluated in accordance with Fransen et al., 2011, with a cut-off score of above 2 indicating a solid health literacy.

Shared decision making

In order to assess the variable, Shared decision making (SDM) and the perceived level of involvement in the decision-making process, two tests were used.

The '**Patient version 9-item Shared Decision Making Questionnaire (SDM-Q-9)**' was used for measuring the patients perceived level of SDM. This questionnaire is the short form and newest version of the original Shared Decision Making Questionnaire (SDM-Q) (Kriston et al., 2010). The SDM-Q-9 was detected to be a strongly valid and reliable measure with the factor analysis revealing clearly one factor of the underlying construct. Additionally, a strong internal consistency was found (Cronbach α = .938) (Kriston et al., 2010). Due to the elderly sample that the questionnaire was tested on, the generalizability might be limited (Kriston et al., 2010). However, as the sample of this study has an average age of 62, this test might be well fitting. The SDM-Q-9 measured 9 items on a 6 point likert scale, which ranged from 'totally disagree' to 'totally agree'. Example items are "My doctor wanted to know

exactly how I want to be involved in making the decision", "My doctor asked me which treatment option I prefer", as well as "My doctor and I selected a treatment option together". The raw scores of the items were summed up in order to receive the total scale score ranging from 0-45. Additionally, each individual total scale score was transformed into scores ranging from 0-100 by performing a linear transformation. This was done in accordance with the scoring manual of the questionnaire (Bomhof-Roordink et al., 2021). The computed Cronbach's alpha coefficient for the current study showed a value of 0.95, demonstrating a high reliability.

The second questionnaire that was used to measure SDM was the '**CollaboRATE**' questionnaire (Barr et al., 2014). It is a 3-item questionnaire, measuring the patients' perceived level of involvement in the decision-making process. Each of the three items were measured on a 10-point Likert scale, ranging from 0 (No effort at all) to 9 (Made every effort). The exact formulation of the items were "How much effort was made to help you understand your health issues?", "How much effort was made to listen to the things that matter most to you about your health issues?", and "How much effort was made to include what matters most to you in choosing what to do next?". The psychometric properties of the questionnaire demonstrated good reliability and validity measures making the 'CollaboRATE' questionnaire widely accepted for routine clinical use (Barr et al., 2014). The computed Cronbach's alpha coefficient for the current study displayed a value of 0.97, indicating a strong internal consistency.

Other variables

Besides the measures that were scrutinized within this study, multiple additional variables have been assessed which were not part of the scope of this study. Those variables encompass: Organization of aftercare, Organization of follow-up, Organization of anti-hormonal therapy, Illness perception, Cancer worry, Risk perception, Outcome information, Quality of life, and Decision related knowledge.

Analysis

The dataset used for this study was analyzed using the statistical program SPSS (statistical package for social science) (Wagner III, 2019). Furthermore, the dataset assessed the descriptive statistics of the demographic variables, which included the mean, variance, standard deviation, and percentiles.

With the aim of evaluating the normality of the data, using the psychometric properties Skewness and Kurtosis (Appendix 2). According to Hair (2010) and Byrne (2016), normality

can be assumed when the Skewness value ranges between -2 and +2, as well as the Kurtosis value ranging between -7 and +7. Hence, all variables 'Age', 'Health literacy', and 'Shared decision making' were displayed to be normally distributed (Appendix 1). Therefore, parametric tests were conducted.

In order to get some first insights into the results with the aim to examine the research question "To what extent is the decision about post-treatment surveillance currently a shared decision?", a descriptive analysis was performed. The variables 'Age', 'Health literacy', and 'Shared decision making' were analysed in the matter of their means (M), standard deviations (SD. The variables 'Marital status', 'Occupation', and 'Education' were analysed in the form of their frequencies and percentages.

To examine the first research question "To what extent is the decision about post-treatment surveillance currently a shared decision?", both measures of the variable SDM were analyzed in terms of their means (M) and standard deviations (SD).

To examine the second research question "To what extent are shared decision making, age and health literacy associated with each other?", a pearson's r correlation was calculated. The evaluation of the correlation coefficient was done in accordance with Schober, Boer & Schwarte (2018). A correlation coefficient ranging between 0.00 and 0.29 was interpreted as a weak correlation. A correlation coefficient of 0.30 to 0.59 was considered to be a moderate correlation, and coefficient of 0.60 to 1 was defined as a strong correlation (Schober, Boer & Schwarte, 2018).

In order to examine the third research question "Is the relationship between Age and Shared decision making moderated by Health Literacy?", a moderation analysis was performed. Both independent variables 'Age' and 'Health literacy' were first centred around the mean so that each of those variables are still adequately interpretable even when no interaction effect is found. Afterwards, the interaction effect variable has been calculated by multiplying age (mean centred) with health literacy (mean centred). Finally, a two-tailed multiple linear regression analysis was applied to examine the moderation effect as well as each individual effect of the independent variables 'Age' and 'Health literacy' on the dependent variable 'Shared decision making'. The significance level was set at $p \leq 0.05$. Due to the dependent variable 'Shared decision making' being measured by two separate questionnaires, two moderation analyses were conducted with the SDM Q-9 being the dependent variable (Table 4) and with the CollaboRATE being the dependent variable (Table 5).

Results

Description of the study group

The age of the participants ranged from 31 to 85 years, with the average age of 62 years. In regards to the participants' health literacy the average score was 3.6. This means that participants had a high health literacy. Precisely, 93% of the participants had a high level of health literacy. The biggest proportion of the participants reported to be living together with a companion (73.8%). Furthermore, more than half of the participants reported to not have a paid job (56.3%). Besides, approximately half of the participants indicated a middle education level (51.2%).

Table 1

Demographics (N=252)

	Characteristic	Range	Mean (SD)	N	%
1.	**Patients age in years**	31--85	62 (10.11)		
2.	**Marital status**				
	Widow			22	8.7
	Divorced			13	5.2
	Single			27	11.1
	In a relationship			3	1.2
	Living together/married			187	73.8
3.	**Occupation**				
	Not having a job			142	56.3
	Having a job			110	43.7
4.	**Education**				
	Low			33	13.1
	Middle			129	51.2
	High			90	35.7
5.	**Health literacy**	1.3-4	3.6 (0.4)		
	Low			4	1.6
	High			248	98.4

Prevalence of SDM

In order to answer the first research question "To what extent is the decision about post-treatment surveillance currently a shared decision?", a descriptive analysis was performed with two separate instruments, namely the SDM Q-9 and the CollaboRATE. Both instruments revealed relatively similar results (Table 2). Namely that the participants perceive SDM to take place occasionally.

Table 2

Descriptives of the Variable 'Shared Decision Making' Separately Measured by the SDMQ-9 and CollaboRATE (N=249)

	Variables	Mean	SD
1.	**SDMQ-9**	51.43	31.52
2.	**CollaboRATE**	5.74	3.03

SDM

The results of the SDM Q-9 revealed that the participants' average perception of SDM taking place was moderate, as the average reported score was 51.43.

The outcome of the descriptive analysis for the CollaboRATE showed that the average score of the participants' perceived shared decision making was revealed to be 5.74, indicating shared decision making being perceived as taking place moderately.

Therefore, to answer the research question on the basis of both questionnaires (CollaboRATE and SDM Q-9), Shared decision making is currently taking place occasionally .

To what extent are   age   and   health literacy   associated with SDM

In order to examine the research question "To what extent are   age and health literacy associated with SDM   ?", a correlational analysis using pearson's correlation coefficient has been conducted (Table 3).

Table 3

Bivariate Correlations of the Variable's Age', 'Health literacy', 'SDMQ-9', and 'CollaboRATE' (N=249)

Variables	1	2	3
1. Age	-		
2. Health Literacy	**-0.14***	**-**	
3. SDMQ-9	**0.21****	**-0.15***	-
4. CollaboRATE	0.09	-0-10	**0.73****

Note. significant correlations are in boldface; *Correlation is significant at the 0.05 level (2-tailed); **Correlation is significant at the 0.01 level (2-tailed

Association between 'Age' and 'Shared decision making'

To detect whether age is associated with the participants perception of SDM (measured by the SDM Q-9), a pearson's r coefficient was calculated (Table 3). The results revealed a weak positive correlation between the two variables. Those results disclosed that older participants perceived a higher level of SDM. The outcome of the CollaboRATE questionnaire showed no significant correlation between 'Age' and 'Shared decision making'.

Association between 'Health literacy' and 'Shared decision making'

For evaluating whether 'Health literacy' is associated with 'Shared decision making' measured by the SDM Q-9, a pearson's r correlation coefficient has been calculated (Table 3).

The test outcome displayed a negative weak correlation of 'Health literacy' and 'Shared decision making' (measured by the SDM Q-9), meaning that women   with   lower health literacy reported a higher level of perceived SDM.

No significant correlation   between 'Health literacy' and 'Shared decision making' (measured using the CollaboRATE scale) was found.

Is the relation between age and shared decision making moderated by health literacy?

In order to answer the research question whether the relationship between 'Age' and 'Shared decision making' is moderated by 'Health literacy', moderation analyses were conducted using multiple linear regressions (Table 4 and Table 5).

A significant model was found when using the SDM Q-9 [$F_{(3,245)}$=5.751; $p<0.05$], with an adjusted R2 of 0.054, meaning that all predictors together can explain 5% of the variance in the dependent variable, which can be considered as little (Table 4). The results disclosed that the variable 'Health literacy' neither moderated age, nor had an effect on SDM. However, age was found to have a significant effect on SDM.

When using the CollaboRATE, no significant model was observed [$F_{(3,245)}$=1.551; p=0.202], with an adjusted R2 of 0.007 (Table 5). Accordingly, the variables 'Age', 'Health literacy' and 'Moderation effect' were found to have zero effect on SDM.

Consequently, it can be stated that when using both, the SDM Q-9 and the CollaboRATE, no moderating effect of the variable 'Health literacy' on the relationship of 'Age' and 'SDM' could be detected. Hence, the relation of age and SDM is not moderated by health literacy.

Table 4

Moderation analysis of Age, Health literacy, and the moderation effect on shared decision making, assessed with SDMQ-9 (N = 249)

Variable	B	SE	β	CI (95% lower)	CI (95% upper)	t	p
Constant	51.122	1.959		47.263	54.980	26.095	0.000
Age (mean centered)	0.613	0.195	0.196	0.230	0.996	3.149	0.002
Health literacy (mean centered)	-6.224	4.131	-0.098	-14.361	1.924	-1.506	0.133
Moderation effect (age*HL)	-0.479	0.373	-0.083	-1.213	0.256	1.283	0.201

Note. Dependent variable: SDMQ-9; Adjusted R^2 = 0.054; $F_{(3,245)}$ = 5.751; $p<0.05$

Table 5

Moderation analysis of Age, Health literacy, and the moderation effect on shared decision making, assessed with CollaboRATE (N = 249)

Variable	B	SE	β	CI (95% lower)	CI (95% upper)	t	p
Constant	5.721	0.196		5.335	6.107	29.183	0.000
Age (mean centered)	0.023	0.019	0.074	-0.016	0.061	1.164	0.245
Health literacy (mean centered)	-0.478	0.413	-0.077	-1.293	0.336	-1.157	0.248
Moderation effect (age*HL)	-0.031	0.037	-0.054	-0.104	0.043	-0.821	0.412

Note. Dependent variable: CollaboRATE; Adjusted R^2 = 0.007; F(3,245) = 1.551; p=0.202

Discussion

The first research question was to examine to what extent the decision about post-treatment surveillance is currently a shared decision. The results revealed that the decision is currently made occasionally in a shared decision. Hence, approximately some patients perceived SDM to take place quite extensively, while other patients did not feel extensively included in the decision making process. Especially in comparison to results of previous studies, it seemed like shared decision making can be improved. Calderon et al., (2018) and Rodenburg-Vandenbussche et al., (2015) who also examined SDM in a breast cancer sample, found a significantly higher extent to which shared decision making is perceived to take place in oncology practice. Their results of the SDM Q-9 showed means of 73.00 (Rodenburg-Vandenbussche et al., 2015) and 63.20 (Calderon et al., 2018), while the current study only displayed a mean of 51.43. Also the results of the CollaboRATE were different comparing the current study (M=5.74) with the results of Hurley et al. (2019), (M=8.48) and those of De las Cuevas et al. (2020), (M=8.48). These differences might be explained through the specific differences of the samples. The sample of the current study examined breast cancer patients who are in the post treatment surveillance phase, while for instance Calderon et al., (2018), investigated a broader sample of cancer patients, including cancer patients in different stages

of their treatment procedure, and consequently also with different decisions to take. Also, Calderon et al., (2018) used broader inclusion criteria, which resulted in the sample consisting of almost 45% of men. In the current study, the sample consisted solely of women. Hence, it might be possible that the participants gender might have affected the results in regards to perceived SDM. However, for future research purposes, it would be interesting to further investigate which other factors influence the extent to which SDM currently takes place in post treatment surveillance of breast cancer patients. Therefore, examining whether the extent of SDM is dependent on the patients' preferences regarding taking part in the decision making process would be interesting, since it was not measured within this study. Therefore, the theory of planned behaviour could be used, adding attitude, subjective norm, and perceived behavioural control as variables.

The second research question investigated to what extent age and health literacy are associated with SDM. First the variables age and SDM were assessed. According to the outcome of the SDM Q-9 older women reported higher levels of SDM. Surprisingly, no association was found between age and SDM (measured byCollaboRATE), despite 'SDM Q-9' and 'CollaboRATE' both measuring SDM. This was validated by a significant strong positive correlation between the two questionnaires. Nevertheless, the results of Galesic, & Garcia-Retamero (2011) displayed an association between age and shared decision-making preferences. Another study found a more detailed relationship between the two variables describing that the preference of involvement in the decision-making process declines with increasing age (Schneider et al., 2006). Those results of other studies however are not in line with the results of the current study. A possible reason for that might be the high health literacy sample that participated in the current study. As almost all participants reported high levels of health literacy, it might be possible that this impacted age to become positively associated with SDM. Thus, further research should investigate whether health literacy serves as a mediating factor with regards to the relationship of age and SDM in post treatment surveillance cancer patients.

Secondly, it was checked if the variables 'Shared decision making' and 'Health literacy' disclose an association. The results displayed that patient's with a lower health literacy reported higher levels of SDM. Kim et al. (2001), found an association between health literacy and SDM. They specified this association by finding that a low health literacy serves as a barrier to patient participation in SDM due to their problems of understanding complex health related information (Kim et al., 2001). Another study confirmed the results of Kim et al. and complemented them, as they found that sufficient health literacy is necessary for patients in

order to have a more patient-centred care experience, as well as increasing the likelihood of being more satisfied with the received health-care (Altin & Stock, 2016). Those findings however are contradictory to the results of this study, since the association detected in this study was negative. One possible factor for those contradictory results is that the sample of the current study consisted of both, relatively old as well as high health literacy participants. Even though research suggests that health literacy and SDM are positively associated with each other (Altin & Stock, 2016; Kim et al., 200), research also suggests that the interest in SDM declines with an increasing age (Schneider et al., 2006). Hence, it might be possible that the age of the participant was the crucial factor for the negative association between health literacy and SDM within this sample. This is also supported by the results of the moderation analysis, which revealed health literacy to have no effect on SDM, and hence detected age to be the only significant predictor of SDM. As a result, future research could examine the extent to which health literacy and age affect SDM more closely, in order to find out whether age can generally be expected as the dominating factor over health literacy when predicting SDM. Additionally, it needs to be examined which factor of the two (age and health literacy) could possibly act as a confounding variable. Further findings in that matter can   help   in shifting the decision-making process towards a more extensive shared decision within the post treatment surveillance of breast cancer patients.

        The third research question was to examine if the relationship between 'Age' and 'Shared decision making' is moderated by 'Health literacy'. The results of the moderation analysis revealed that no moderation effect was detected. However, the outcome of the variables 'Health literacy' and 'Age' showed that 'Age' was the only significant predictor of 'Shared decision making'. The relationship of 'Age' and 'Shared decision making' according to the moderation analysis is positive, but weak. This means that older participants reported higher levels of SDM, and that age predicts SDM to a small extent. However, it is difficult to link and compare those results to previous studies, as the moderation of health literacy on age and SDM in post treatment surveillance breast cancer patients has yet not been extensively investigated. However, according to Galesic, & Garcia-Retamero (2011), SDM is negatively associated with age.   One possible explanation of contradictory results might be that this sample was composed of mainly older participants (see mean age Table 1). Hence, it might be possible that perceived SDM is only dependent on age to a certain extent. To clarify, scores of shared decision making might stop decreasing at a certain (old) age, which means that it might be possible that age might not be an influencing factor of SDM among old people. However,

this is just a speculation, which should be further investigated to   be rejected or validated through further research   .

The same moderation analysis with 'CollaboRATE' as the dependent variable showed different results in comparison to the outcome of the analysis with the SDM Q-9. Here no significant model was found, and therefore no moderation effect or individual effect of the variables 'Age' and 'Health literacy' could be detected. However, one possible reason for the results of both, the SDM-Q9 and the CollaboRATE to differ slightly, might be that the CollaboRATE is a 3-item questionnaire which is measuring SDM to a broader extent compared to the 9-item SDM Q-9. The CollaboRATE questionnaire has its strengths in just detecting the absence or presence of shared decision making, for which it is especially effective. The SDM Q-9 on the other hand, is the lengthier measurement instrument which provides more detailed information about shared decision making (Barr et al., 2014). This difference in the precision of both intstruments in measuring SDM could have caused the contradictory results of the SDM Q-9 and CollaboRATE in the current study.

Apart from the aim of the study, a further finding is worth mentioning. Increasing age was detected to be associated with a decreasing health literacy. These results are in line with those of other studies. Accordingly, Ashida et al. (2011), found a significant effect of age on health literacy. Participants with an increased age showed a significantly decreased health literacy, than those patients who were of younger age (Ashida et al., 2011). Also in line with the outcomes of the current study are the findings of Baker et al. (2000), whose results showed a strong association between health literacy and age. They found that health literacy was significantly lower for older age groups, even after controlling for potential confounding variables (Baker, et al., 2000). Future research should therefore aim at identifying methods that are effective in helping the older population remain or (re)gain their health literacy in order to enhance their perception of a more patient-centred communication (Wynia & Osborn, 2010). This in turn can improve the patient's experience and outcome of the received care, which can lead to a higher satisfaction rate among older patients (Wynia & Osborn, 2010). For practice, it can be suggested that general health care professionals (HCP) should adjust their way of informing when talking to advanced age patients. Research suggests that HCP should invite their patient's to ask questions. Further, communication skill training for HCP's might increase the health literacy of the patients (Coulter & Ellins, 2007). Additionally, in order to enhance both, the preference for taking part in the decision-making process, as well as the patients satisfaction with the received health care, people with increasing age should be suggested to make use of literacy-sensitive materials, through which these skills can prosper (Coulter &

Ellins, 2007). Therefore, research promotes a combination of personalised written and verbal information that is most effective for enhancing health literacy (Coulter & Ellins, 2007).

Strengths and limitations of the study

A strong point of this research paper is that it centres breast cancer patients who were receiving follow-up care at the time of the data collection. Previous studies rather focused on breast cancer patients that were at a different stage of treatment or diagnosis. This means that this research paper adds findings to the relatively small knowledge pool of this still quite uninvestigated area of research.

A potential limitation of this study that should be considered is the length of the survey and the corresponding time participants needed to fill out the survey. All in all, the survey encompassed a total of more than 110 items, which consequently takes quite some time to complete. Hence, the participants' motivation might decrease over time, which in turn can result in faster, shorter, less precise, and more uniform responses for later items of the survey (Galesic & Bosnjak, 2009). Especially for the variable health literacy this might be important to notice. The lengths of the questionnaire could have caused low health literacy patients to quit the questionnaire before finishing it. Some participants might have finished the whole questionnaire but might have answered faster, less precisely and more uniformly due to their low health literacy. Hence, this might explain why participants with a lower health literacy reported higher levels of SDM. One indicator for this is that a number of participants did answer early items in the questionnaire but stopped at some point and never answered the latter items of the questionnaire. This can also be observed in the descriptive statistics, when comparing the number of valid participants of the demographic variables with the number of valid participants of the SDM Q-9 and CollaboRATE.

Another factor that needs to be taken into account is being aware of the publication bias (Kühberger, Fritz & Scherndl, 2014). It is described as the finding of nonsignificant results, which were, due to the fact of being insignificant, not published (Kühberger et al., 2014). Within the subject of psychology this is a common sensation, which consequently can lead to a misperception, giving the idea that one should expect differences, when previous research did also not detect any differences (Kühberger et al., 2014). Another trick used by researchers is known as the inflation bias. This can be described as a method to turn insignificant statistical results into statistically significant ones (Simmons et al., 2013; Head et al., 2015). Keeping that in mind, the results of accessible research papers should always be interpreted with caution.

Additionally, this could at least partially indicate why some results of this study are different from previous findings.

Furthermore, another weak point of the study is that the sample is really specifically selected due to the inclusion and exclusion criteria. This makes it difficult to generalize the results and make correct inferences. However, since the study was not designed to deliver generalizable results, but rather really specific results within the setting of Santeon hospitals, it can be stated that even though the results are not generalizable, they are applicable within the examined population and setting of this sample.

Conclusion

This study has shown that currently SDM takes place to a moderate extent in breast cancer post treatment surveillance. Increased age was associated with higher scores in SDM, as well as with lower scores in health literacy. Additionally, lower health literacy was associated with higher SDM.

The moderation analysis disclosed that age is an influencing factor in the perceived extent of   SDM. Hence, especially younger breast cancer patients should be encouraged more to take part in the decision-making process.   Further   research should aim   at the further investigation of factors that influence   patients' perception of SDM in post treatment surveillance. This is important because the current extent of SDM in post treatment surveillance can be significantly improved.

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Appendix 1

Table 1

Skewness and Kurtosis (N=252)

Variable	Skewness Statistic	SE	Kurtosis Statistic	SE
1. CollaboRATE	-0.68	0.15	-0.89	0.31
2. SDMQ-9	0.02	0.15	-1.00	0.31
3. Age	-0.19	0.15	-0.27	0.31
4. Health literacy	-1.58	0.15	3.04	0.31