Patient-Reported Outcome Measures and Shared-Decision Making- Outcome Information Needs, Preferences of Women for Breast Cancer Follow-Up Treatment.

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Abstract

Background: Shared decision making (SDM) about breast cancer surveillance can help women and health professionals to individualise breast cancer follow-up treatment. However, SDM can cause helplessness and anxiety among women who do not know their needs and preferences. Therefore, outcome information can help women to find the most suitable follow-up treatment. Patient-reported outcome measures (PROMs) can help to find preferred and needed outcome information. In this study, outcome information were assessed to see which type of outcome information women desired and if they obtained these information. and to what extent they are associated with age and health literacy.

Method: The study sample includes 266 women one year after curative treatment for invasive breast cancer. Data on outcome information was obtained using a self-constructed questionnaire, assessing the (1) type of outcome information that women received and to which extent (2) they considered this type of information important. Health literacy was assessed through the SBSQ questionnaire (Fransen et al., 2011). Their answers were ranked in two tables from most to least obtained and from most to least desired outcome information. Pearson's correlations were used to explore the association between obtained, desired outcome information with age and health literacy.

Results: The results show that the most desired outcome information was information about physical complaints (M = 2.4, SD = 0.8) and fatigue (M = 2.3, SD = 0.8). The most obtained outcome information were fatigue (M = 1.6, SD = 0.8) and physical complaints (M = 1.5, SD = 0.8). The biggest difference between desired and obtained information occurred for risk of dying and risk of recurrence. Age was most strongly associated with (less) obtained information about psychosocial complaints (r = -0.34, p<0.01) but also less desired information about psychosocial complaints (r = -0.37, p<0.01). There were no significant associations found between health literacy and any of the obtained and desired types of outcome information.

Conclusion: The most obtained and desired outcome information about fatigue and physical complaints match each other. The biggest difference is between outcome information about risk of recurrence and dying. The women desire more information about it than they obtain. Age is mostly significant negatively associated with all obtained and desired outcome information whereas health literacy is mostly not significant associated with any outcome information. Therefore, for further research it would be useful to find out why risk is not communicated and additionally find outcome information for older women.

Keywords: PROMs, age, health literacy, obtained, desired, post-treatment, cancer, surveillance, SDM, outcome information

Introduction

Breast cancer is a severe disease for women worldwide. In the Netherlands 17,000 women are being diagnosed with breast cancer every year (Filipe et al., 2020). Furthermore, 3,000 women die every year of its consequences. This shows a high survival rate. (McWilliams et al., 2020). Therefore, more women need to live with breast cancer and need more follow-up care. Follow-up care consists of aftercare and post-cancer surveillance. Aftercare is providing psychological care and detecting and treating any (long term) effects of breast cancer. Post-cancer surveillance aims at detecting local recurrence in an early stage (Klaassen, Dirksen, Boersma, & Hoving, 2018). Currently, this follow-up care is a one size fits all (annual mammogram and/or MRI for 5 years) (Lafranconi et al., 2017). This kind of follow-up treatment can have an impact on women's physical, social and mental life (Corner et al., 2013). Annual mammograms and/or MRI can cause physical complaints like fatigue and or movement restrictions. Psychosocial complaints like going back to work and anxiety and depression can also occur (Brandzel et al., 2017). To reduce these complaints women, need to co-decide about the intensity and mode of follow-up care.

Shared-Decision Making

Deciding for breast cancer follow-up treatment is more or less a preference and sensitive decision, and in these cases, shared-decision (SDM) making is recommended**.** During SDM patients and health care professionals (HCP) decide together which kind of treatment fits the best for the patient. According to studies, it is a preferred method of medical decision making (Engelhardt et al., 2020). This is particularly used in decisions where there is no ´best option´ (Edwards et al., 2005). An advantage for SDM is a particular increase in adherence to the treatment (Lafranconi et al., 2017). If the survivors are involved in their own decision to the breast cancer follow-up treatment options they can feel in charge of their own choice. In addition, women get an increase of knowledge about their treatment and the tendency to regret their decision during the follow-up treatment is decreasing (Moudi, Phanodi, Ansari, & Zohour, 2018). However, being in charge of further treatment is a situation that can put some women in an anxious state (Engelhardt et al., 2020). Another disadvantage is pushing patients to make decisions they do not feel able to make. To reduce the anxiety and be able to be part of decision making, they should be well informed. This should include information about the procedures and treatments but should also consist of outcome information.

Outcome Information

Outcome information can be used to describe what a client or patient achieved, did or say about treatment. Outcome reports are presenting the data on outcome information. These reports can be prepared in a specific time frame (Thompson, Sirio, & Holt, 2000). Deciding for a suitable breast cancer follow-up outcome information can be clinical (e.g., focusing on early recurrence detection) which can be useful for post-cancer surveillance. Furthermore, outcome information can also be Patient-reported (PROM) which can be useful for aftercare treatment. PROMs can be systematically collected and can give reliable information about patients' experience about outcome information, what they needed and preferred (Corner et al., 2013). This can have the result that patient-orientated outcomes, measured with PROMs, can be different from the clinical-orientated outcome (Kool et al., 2016). Therefore, with outcome information, women can report on their preferences and needs based on their experience (Corner et al., 2013). Examples of relevant outcome information for breast cancer follow-up care are physical and psychosocial complaints as well as the risk of recurrence and dying. In research, the most desired needs for women in active breast cancer treatment are fewer breast cancer symptoms like the aforementioned physical and psychosocial complaints (Kool et al., 2016). However, currently little is known about how information provision looks like, and which information is desired. Furthermore, it is also not much known if different women have different information needs or get other information.

Demographics

Age. One differentiation factor, to individualize outcome information, age can be taken into account. It is assumed that quality of life (QoL), is declining around the age of 70 (Nielsen et al., 2021). Furthermore, younger women may be more concerned about their physical appearance and femininity which has an impact on psychosocial complaints (Rose et al., 2020). It is also seen that younger women have difficulties coping with the diagnoses of cancer first of all and later with the side effects of follow-up treatment (Wenzel et al., 1999). Moreover, younger women are more considered to have a problem maintaining a positive attitude (Coyne, 2009). Therefore, it is important to know for women and HCPs which kind of information needs different age groups to enhance SDM about follow-up treatment and to improve information provision (Vivar & McQueen, 2005). Moreover, this can help women to reduce anxiety, knowing what types of outcome information is most associated with their age.

Health literacy. Another factor that may affect wishes for outcome information is health literacy. Health literacy is the ability to manage self-care regarding physical complaints and social and psychological distress (Kim & Han, 2019). It includes individual awareness and the ability to maintain and /or improve their state of health. Not only adhering to medication is important, but complex competencies like reading, analysing, listening, integrating, comprehending and integrating are also part of proper health literacy (Wei, Wu, & Tung, 2021). It is important for women when they start post-cancer surveillance to stay motivated to understand the implemented decision making to organise their follow-up treatment to improve or maintain their QoL (Kim & Han, 2019). Therefore, health literacy could influence women's information needs. It is assumed that breast cancer patients with lower health literacy have a higher information need than patients with higher health literacy (Halbach et al., 2016). However, thus far it is known for breast cancer treatment. In this research, health literacy is associated with outcome information about breast cancer surveillance to examine whether lower health literacy is associated with higher information needs.

Purpose of the Study

This leads to two research questions.

- Which types of outcome information breast cancer patients consider as important to be able to make decisions about post-treatment surveillance and aftercare and which types of outcome information they actually receive?
- To what extent are the obtained and desired outcome information related to the women's age and their level of health literacy?

This research is analysing if the desired needs and preferences of women were also obtained. Furthermore, more outcome information and demographics were studied to find out if women have more needs and preferences than the known two (i.e., physical, and psychosocial complaints).

Method

Design

This study was part of the larger PhD study by Jet Ankersmid. For this larger study, data were collected using a Multiple Interrupted Time Series (mITS) design. This current research paper investigated only research questions referring to the pre-implementation (baseline) data. A correlational design was adopted to examine the role of the variables obtained and desired outcome information, age, and health literacy.

Participants and Procedure

The survey was ethically approved by the declaration of Helsinki (World Medical Association, 2001). To be eligible to participate in the study, a patient had to meet all of the following criteria: (1) patient who faced the decision for the organisation of follow-up care after receiving curative treatment for invasive breast cancer, (2) patients who had to access and experience with using a PC, laptop or tablet with an internet connection or could have been assisted by their caregiver, (3) patients who were treated in a Santeon hospital, (5) patients who were 18 years or older, (6) patients who understood the Dutch language in speech and writing and were able to provide informed consent. A patient who met any of the following criteria was excluded from participation: (1) patients diagnosed with non-invasive breast cancer (e.g., Ductal Carcinoma In Situ (DCIS)), (2) patients who received palliative treatment, (3) patients who received neoadjuvant therapy (4) male breast cancer patients and (5) patients who were not able to fill in the questionnaire, not even with extensive help. The patients were recruited through a consecutive sample by asking the Santeon HCP to screen their patients. After this, the coordinating investigator (or her representative) contacted the potential participant and asked if she was interested in participating. Furthermore, the coordinating investigator elaborated on the study and answered any questions. When the potential participant agreed to participate, the coordinating investigator asked to sign two informed consent forms and returned one by mail in a provided return envelope. This informed consent form was stored in the Santeon hospital where it was acquired.

Instruments

Personal background

Demographic factors such as age, marital status (1= widowed, 2= divorced, 3= single, 4= in a relationship, 5= living together/married), educational level (1= low (no education, primary education or vocational education) 2= middle (secondary general education, secondary vocational education and vocational guidance, higher general and preparatory scientific education), 3= high (higher vocational education, scientific education)), and occupation (0= not paid job (disabled, pension, voluntary/ unpaid job, household tasks, studying/training), 1= paid job (paid job, for … hours, other) were measured.

Health literacy

For assessing Health literacy, the 3 items of the Set of Brief Screening Questions (SBSQ) (Fransen et al., 2011) were used. The patients had to answer three questions like *"How often do you need help to read letters written by health care professionals"* with a 5-point Likert scale from 0 *never* to 4*´always´*. According to Fransen et al. (2011), an average score of 2 concludes an inadequate health literacy and a score above 2 indicates adequate health literacy. The scale shows a reliability in this current study of Cronbach's alpha of 0.54. Even though this reliability is too low it was decided to continue with this scale because removing items would not increase Cronbach's alpha. Moreover, previous studies like Duong et al. (2017) and Fransen et al. (2011) showed a reliable Cronbach's alpha > 0.69.

Desired and obtained outcome information

The variable ´outcome information´ was assessed with two self-constructed questionnaires. Both contain 11 items about outcome information. The first questionnaire was asking about obtaining outcome information. With questions like "*Did the HP speak with you about possible physical complaints (for example lymphedema in arms or movement restriction) as a consequence of breast cancer and treatment?",* the patients could answer within three options *´Yes´, ´No´* or *`I do not remember´*. An overview of all included types of outcome information can be found in Table 2. This scale showed an acceptable reliability of a Cronbach´s of 0.77. The second questionnaire was asking about desiring different outcome information (topics the same as those described above, see also Table 3). The patients were asked *"How important is the information about possible physical complaints (for example lymphedema in arms or movement restriction) as a consequence of breast cancer and treatment?"* Patients had to answer those questions with a 4-point Likert scale from 0*´not important ´* to 3*´very* *important´.* The higher the number the more important and therefore desired was the type of outcome information. This scale showed a high reliability of Cronbach's alpha of 0.92.

Other variables / outcomes measures

For the original study, the questionnaire entailed various constructs and, which were not analysed in the current study. These are the organization of hormone therapy, the organization of the aftercare as well as the organisation of the follow-up. Furthermore, shared decision making, and fear of cancer recurrence (FOCR). Moreover, the Quality of Life (QoL), excessive examination and risk perception, as well as illness perception.

Data Analysis

The data analysis was conducted with SPSS version 25 (International Business Machine Corporation). Demographic variables such as age, marital status, education level, occupation, and health literacy were partially grouped and computed with descriptive statistics (mean, SD, frequencies etc). After creating the new variables, the data were tested about normality to use appropriate measurement instruments. Therefore, the data were analysed using the psychometric properties Skewness and Kurtosis. Reasonable cut-off for Skewness between values of -2 to +2 and Kurtosis values of -7 to +7 were adopted (Byrne, 2016; Curran et al., 1996). All variables were found to be normally distributed (Appendix 1).

Afterwards, descriptive statistics (age, health literacy) were analysed to get the first insights into the study population.

To answer the first research question, the descriptive statistics of obtained outcome information were analysed and put in a table in order from most obtained to least obtained outcome information. They were analysed by their means *(M)* and standard deviation *(SD)* as well as their total numbers *(n)* and their frequency *(%)* for every type of obtained outcome information. Furthermore, the descriptive statistics of ´desired outcome information´ were analysed, combined in a table from most desired to least desired outcome measures. They were also presented with their means *(M)* and standard deviation *(SD)* as well as their total numbers *(n)* and their frequency *(%)* for every type of desired outcome information. Moreover, the tables of the descriptive statistics tables of ´obtained outcome information´ and ´desired outcome information´ were compared by their ranking of the different types of outcome measures.

The association between the variables age and health literacy with all ´obtained outcome information´ items and ´desired outcome information´ were analysed with a 2-tailed Pearson correlation. The correlation was interpreted as followed: correlation coefficient from 0.00 to ±0.39 it is considered as a weak correlation, correlation coefficient from ± 0.40 to ± 0.69 were understood as a moderate correlation and lastly correlation coefficient ranging from ±0.70 to ±1 it was read as a strong correlation (Akoglu, 2018)

Results

Description of the Study Group

The division of the demographic variable can be seen in Table 1. The age of the participants ranged from 31 to 85 years, with an average age of 62 years. Two-thirds of the women were married or living together, and the majority reported not having a paid job. The most represented degree was middle educational level. Regarding the participants' health literacy, the scores ranged from 1.3 to 4 with an average score of 3.6. Therefore, 92% scored above 2, which is indicative of general high health literacy.

Table 1

Patients' characteristics (n= 252)

	n	%
Marital Status		
Widowed	22	8.3
Divorced	13	4.9
Single	27	10.2
In a relationship	3	1.1
Living together/married	187	70.3
Occupation		
Not having a paid job	142	53.4
Having a paid job	110	41.4
Education		
Low	33	12.4
Middle	129	48.5
High	90	33.0
Health literacy		
Low	2	0.8
High	250	94

Patients´ characteristics age (n= 252) health literacy (n= 237)

	Mean	SD	Min	Max
Age	61.6	10.1	31	85
Health literacy	3.6	0.4	1.3	4

Description of obtained and desired outcome information

Table 2 shows the obtained outcome information of the patients. It shows that two-thirds of the women have received outcome information of fatigue and physical complaints. Furthermore, more than half of the women obtained outcome information about pain complaints and emotional and mood problems. Less than 46% got outcome information about psychosocial complaints and side effects of hormone therapy. The least obtained outcome information was on the number of patients taking medicines every day (23%).

Table 2

Obtained outcome information (n=259)

			No (0)		I do not remember (1)		Yes (2)	
	Mean	SD	n	%	n	%	n	%
Fatigue	1.6	0.8	45	17	16	6	186	70
Physical complaints	1.5	0.8	54	20	11	4	182	68
Pain complaints	1.5	0.8	56	21	22	8	169	62
Emotional and mood problems	1.3	0.9	78	29	28	11	141	53
Psychosocial complaints	1.1	1.0	103	39	23	9	121	46
Side effects of hormone therapy	1.0	1.0	112	41	22	8	113	42
Risk of recurrence	1.0	0.9	102	38	44	17	101	38
Loss of intimacy and sex	0.9	0.9	122	46	24	9	101	38
Risk of dying	0.8	0.9	130	49	33	12	84	32
Stress prior to periodic controls	0.8	0.9	133	50	31	12	83	31
Daily medicine intake	0.6	0.8	150	56	37	14	60	23

Table 3 shows information about desired outcome information. Here it can be seen that outcome information about physical complaints and fatigue were very important for more than 42% of women. Furthermore, more than 40% desired outcome information about pain complaints and risk of recurrence. Here the least desired outcome information is on daily medicine intake. Only for 23% of the women, this was very important. Further distributions can be seen in table 3.

Table 3

Desired outcome information (n=246)

			Not important (0)		Somewhat important (1)		Quit important (2)		Very important (3)	
	Mean	SD	n	%	n	%	n	%	n	%
Physical complaints	2.4	0,8	5	2	28	11	90	34	123	46
Fatigue	2.3	0.8	4	2	39	15	92	35	111	42
Pain complaints	2.2	0.8	2	1	43	16	96	36	105	40
Risk of recurrence	2.2	0.8	3	1	42	16	93	35	108	41
Risk of dying	2.2	0.8	5	2	52	20	84	32	105	40
Emotional and mood problems	2.2	0.9	8	3	45	17	86	32.	107	40
Psychosocial complaints	2.0	0.9	14	5	56	21	86	32	90	34
Side effects of hormone therapy	2.0	1.0	31	12	44	17	84	32	87	33
Loss in intimacy and sex	1.8	1.0	34	13	64	24	76	29	72	27
Stress to prior periodic controls	1.7	0.9	20	8	87	33	81	31	58	22
Daily medicine intake	1.4	1.0	54	20	83	31	69	26	40	15

Both tables show that the most and least obtained and desired and obtained and desired outcome information match each other. The largest difference could be observed between the obtained outcome information of risk of dying, which is ranked 9th on obtained outcome information but 5th on desired outcome information. Another difference is that risk of recurrence is ranked 7th on obtained outcome information and 4th on desired outcome information.

Association of health literacy and age with obtained and desired outcome information

Table 4 shows the correlation matrix of health literacy and age with obtained and desired outcome information. There was no significant association between health literacy and any of the obtained or desired outcome information, except information about loss of intimacy and sex. This means women with lower health literacy levels reported a slightly lower need for information outcomes on intimacy and sexuality. Age was negatively (though weak) associated with nearly all of the desired and obtained outcome information, indicating that older women are getting less information, but also have lower information needs.

Table 4

Correlation matrix obtained age (n = 247) and health literacy (n = 233), desired age (n = 246) and health literacy (n = 232)

	Obtained outcome information		Desired outcome information	
	Age	Health literacy	Age	Health literacy
Physical complaints	-0.12**	-0.07	-0.16*	0.02
Psychological complaints	-0.34**	0.10	-0.37**	0.13
Emotional and mood problems	-0.29**	0.12	-0.28**	0.09
Fatigue	-0.15*	0.11	-0.30**	0.07
Pain complaints	-0.08	0.03	-0.28**	0.05
Loss in intimacy and sex	-0.29**	0.03	-0.36**	0.14*
Stress prior periodic controls	-0.20**	-0.03	-0.26**	0.06
Daily medicine intake	-0.04	0.05	-0.03	0.04
Side effect of hormone therapy	-0.13*	0.06	-0.17*	0.01
Risk of recurrence	-0.17**	0.11	-0.16*	0.12
Risk of dying	-0.26**	0.11	-0.19**	0.12

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Discussion

The main goal of the study was to find out which types of outcome information female breast cancer survivors desired and which they obtained. Furthermore, if there were any differences. The second goal was to identify the associations between age and health literacy with obtained and desired outcome information. The most obtained outcome information in this study were fatigue and pain complaints. This was different than expected. When talking to patients about breast cancer treatment, HCPs rather inform about clinical outcome information which are aiming at disease-free survival like medicine intake or fitting hormone therapy (Kool et al., 2016). Whereas fatigue and pain complaints are rather a patient-orientated outcome measure (Stutts et al., 2009). Moreover, women most desired information about fatigue and pain complaints. A possible reason for this could be that breast cancer therapy causes fatigue and pain complaints and women try to avoid these symptoms for their follow-up treatment (Chopra & Kamal, 2012). Thus, they express more interest in outcome information about fatigue and pain complaints. Moreover, fatigue and pain complaints can have a profound impact on the daily life of women, which can lead to more interest in outcome information for follow-up treatment surveillance (Nielsen et al., 2021). Other types of outcome information, like the psychosocial complaints, were more desired for breast cancer treatment (Kool et al., 2016). However, women do not require this kind of outcome information as much for follow-up treatment. This can be due to the fact that the women were living with breast cancer treatment before follow-up treatment. Therefore, they could learn how to adapt work and social environment to treatment before (Doumit, El Saghir, Abu-Saad Huijer, Kelley, & Nassar, 2010). This can lead to psychological resilience and therefore to lower interest in psychosocial outcome information.

Additionally, the results show a larger difference in obtained vs. desired information on outcome information about the risk of recurrence and the risk of dying. It was found out that 40% of the women desire this risk outcome information and indicted it as very important. However, only 1 of 3 women obtained it from their HCP. A possible reason could be that risk communication is in general a difficult topic to talk about (Edwards et al., 2005). Therefore, it can be useful for HCPs to know how to communicate the risk of recurrence and dying to their patients. In conclusion, it can be said that the most obtained and desired as well as the least obtained and desired outcome information differentiate notably from each other. However, it would be interesting to further investigate why HCPs are not communicating the risk of recurrence and risk of dying to their patients as they wish and if risk information is available for HCPs.

In regard to the second research question, age is significantly negatively associated with obtained and desired outcome information. This means older women obtained less information from their HCPs but at the same time, they also require less of the results listed outcome information. This is in line with previous findings of Rose et al., (2020) here it is stated that older women have a reduced QoL which is associated with less interest in outcome information. Furthermore, it was stated that especially younger patients have more psychosocial problems than older patients (Rose et al., 2020). This study shows the highest negative association with obtained and desired outcome information about psychosocial complaints. This could be due to the lack of concern older women have, for example, do not have to be concerned about going back to their job because most of them are retired. Furthermore, older women mostly do not have to worry about their families, usually, their children are older and do not need care anymore (Sperlich, Arnhold-Kerri, & Geyer, 2011). However, all outcome information are negatively associated with age. Therefore, it could be further researched to find out which type of outcome information are of importance for older women.

Furthermore, the results show that health literacy is associated with neither any obtained nor any desired outcome information. Therefore, women's health literacy does not significantly influence their obtained nor their desired outcome information. However, the tendency between health literacy and desired outcome information is mainly positively associated. Indicating that women with higher health literacy obtained and desired more outcome information than women with lower health literacy. This is in contrast to the study about information needs during cancer treatment. Halbach et al. (2016) assumed that patients with lower health literacy have more information needs than patients with higher health literacy. One possible answer for this could be that high health literate women know about breast cancer and its treatment because of awareness strategies, for example via social media (Abramson, Keefe, & Chou, 2015). Therefore, health literate women could know more about breast cancer treatment. Although little is known about follow-up treatment because it is not as represented as a breast cancer treatment (Hardcastle et al., 2018). Therefore, it could be possible that high health literate women seek more follow-up information. However, this fact about knowledge is just one possible approach. For this reason, it would be interesting to research further why health literate women seek more outcome information and how health literacy can personalise information-seeking behaviour.

Strong /weak points of the study and recommendations

A strong point of the study is the individualisation of follow-up treatment. Furthermore, this study gives an insight into what women think is important for follow-up treatment and it can be used to help other women for deciding for breast cancer follow-up in SDM. Moreover, there exist further articles focusing on breast cancer treatment and SDM, but only a few emphasize breast cancer follow-up treatment and SDM. The study also has some limitations. An aspect that can be seen as a weak point is that the questionnaire first asked if the outcome information was obtained from the HPs and afterwards it asked how desired this outcome information was. This could have a priming effect on the patients. As it is known, priming can have a positive effect on people when they are exposed to a positive stimulus and vice versa (Moss & Lawrence, 1997). Therefore, first answering an outcome information with yes can have a positive effect on answering the desired outcome and therefore bias the results. This could also be the reason why the most and least obtained as well as the most and least desired outcome information are inline. For further research, it would be recommended to first answer how important an outcome information is and afterwards indicate whether it was obtained or not. This can prevent a priming effect. Furthermore, during the data collection, the outbreak of the pandemic COVID-19 started. Breast cancer patients reported emotional struggles and vulnerable cognition. Moreover, oncology visits were reduced. In another research, it would be interesting to find out what impact COVID-19 had for deciding on follow-up treatment and the outcomes (Swainston, Chapman, Grunfeld, & Derakshan, 2020). Another limitation was the low reliability of the health literacy questionnaire (SBSQ), containing three questions. An implication for further research could be another questionnaire that assesses health literacy more reliably.

Conclusion

In conclusion, it was found out that the most obtained and desired outcome information were fatigue and pain complaints. The largest difference between obtained and desired outcome information was about the risk of recurrence and risk of dying. This means the women desired more outcome information about the risk of recurrence and dying than they obtained. Furthermore, the different types of outcome information were associated with age and health literacy. Here the results show that age is significantly weak and negatively associated with psychosocial complaints. For practical implementation, this finding could be part of a debriefing of women who have to face an SDM for breast cancer surveillance. With these findings, the patients can see what other patients their same age perceived as important. Hence, decision making could be easier for patients and HCPs.

References

Akoglu, H. (2018, September 1). User's guide to correlation coefficients. *Turkish Journal of Emergency Medicine*. Emergency Medicine Association of Turkey. https://doi.org/10.1016/j.tjem.2018.08.001

Brandzel, S., Rosenberg, D., Johnson, D., Bush, M., Kerlikowske, K., Onega, T., Henderson, L., Nekhlyudov, L., DeMartini, W., & Wernli, K. (2017). Women's experiences and preferences regarding breast imaging after completing breast cancer treatment. *Patient Preference and Adherence, Volume 11*, 199–204. https://doi.org/10.2147/ppa.s122244

Byrne, B. M. (2016). *Structural equation modeling with AMOS: Basic concepts, applications, and programming*. Routledge. Doi:10.4324/9781315757421

Chopra, I., & Kamal, K. M. (2012, January 31). A systematic review of quality of life instruments in long-term breast cancer survivors. *Health and Quality of Life Outcomes*. BioMed Central. https://doi.org/10.1186/1477-7525-10-14

Corner, J., Wagland, R., Glaser, A., & Richards, M. (2013). Qualitative analysis of patients' feedback from a PROMs survey of cancer patients in England. *BMJ Open, 3*(4), 2316. https://doi.org/10.1136/bmjopen-2012-002316

Coyne, S., & Research Online, G. (2009). *Living the experience of breast cancer treatment: The younger women's perspective Author Link to published version*. *Journal Title Australian Journalof Advanced Nursing*. Retrieved from http://hdl.handle.net/10072/28412http://www.ajan.com.au/

Curran, P. J., West, S. G., & Finch, J. F. (1996). The robustness of test statistics to nonnormality and specification error in confirmatory factor analysis. *Psychological methods, 1*(1), 16. Doi:10.1037/1082-989X.1.1.16

Duong, T. Van, Chang, P. W. S., Yang, S. H., Chen, M. C., Chao, W. T., Chen, T., … Huang, H. L. (2017). A New Comprehensive Short-form Health Literacy Survey Tool for Patients in General. *Asian Nursing Research*, *11*(1), 30–35. https://doi.org/10.1016/j.anr.2017.02.001

Engelhardt, E. G., Smets, E. M. A., Sorial, I., Stiggelbout, A. M., Pieterse, A. H., & Hillen, M. A. (2020). Is There a Relationship between Shared Decision Making and Breast Cancer Patients' Trust in Their Medical Oncologists? *Medical Decision Making*, *40*(1), 52–61. https://doi.org/10.1177/0272989X19889905

Edwards, A., Elwyn, G., Wood, F., Atwell, C., Prior, L., & Houston, H. (2005). Shared decision making and risk communication in practice. A qualitative study of GPs' experiences. *British Journal of General Practice*, *55*(510), 6–13. Retrieved from /pmc/articles/PMC1266236/

Filipe, M. D., van Deukeren, D., Kip, M., Doeksen, A., Pronk, A., Verheijen, P. M., … Richir, M. C. (2020). Effect of the COVID-19 Pandemic on Surgical Breast Cancer Care in the Netherlands: A Multicenter Retrospective Cohort Study. *Clinical Breast Cancer, 20*(6), 454–461. https://doi.org/10.1016/j.clbc.2020.08.002

Fransen, M. P., Van Schaik, T. M., Twickler, T. B., & Essink-Bot, M. L. (2011). Applicability of Internationally Available Health Literacy Measures in the Netherlands. *Journal of Health Communication*, *16*(sup3), 134–149. https://doi.org/10.1080/10810730.2011.604383

Halbach, S. M., Ernstmann, N., Kowalski, C., Pfaff, H., Pförtner, T. K., Wesselmann, S., & Enders, A. (2016). Unmet information needs and limited health literacy in newly diagnosed breast cancer patients over the course of cancer treatment. *Patient Education and Counseling*, *99*(9), 1511–1518. https://doi.org/10.1016/j.pec.2016.06.028

Hardcastle, S. J., Maxwell-Smith, C., Kamarova, S., Lamb, S., Millar, L., & Cohen, P. A. (2018). Factors influencing non-participation in an exercise program and attitudes towards physical activity amongst cancer survivors. *Supportive Care in Cancer*, *26*(4), 1289–1295. https://doi.org/10.1007/s00520-017-3952-9

Kim, K., Han, H.-R. (2019). The Association Between Health Literacy and Breast and Cervical Cancer Screening Behaviors. Nursing Research, 68(3), 177–188. https://doi.org/10.1097/NNR.0000000000000346

Klaassen, L., Dirksen, C., Boersma, L., & Hoving, C. (2018). Developing an aftercare decision aid; assessing health professionals' and patients' preferences. *European Journal of Cancer Care, 27*(2). https://doi.org/10.1111/ecc.12730

Kool, M., van der Sijp, J. R. M., Kroep, J. R., Liefers, G. J., Jannink, I., Guicherit, O. R., Marang-van de Mheen, P. J. (2016). Importance of patient reported outcome measures versus clinical outcomes for breast cancer patients evaluation on quality of care. *Breast*, *27*, 62–68. https://doi.org/10.1016/j.breast.2016.02.015

Lafranconi, A., Pylkkänen, L., Deandrea, S., Bramesfeld, A., Lerda, D., Neamțiu, L., Martinez-Zapata, M. J. (2017). Intensive follow-up for women with breast cancer: review of clinical, economic and patient's preference domains through evidence to decision framework. *Health and Quality of Life Outcomes, 15*(1), 206. https://doi.org/10.1186/s12955-017-0779-5

McWilliams, L., Woof, V. G., Donnelly, L. S., Howell, A., Evans, D. G., & French, D. P. (2020). Risk stratified breast cancer screening: UK healthcare policy decision-making stakeholders' views on a low-risk breast screening pathway. *BMC Cancer*, *20*(1), 680. https://doi.org/10.1186/s12885-020-07158-9

Moss, S. E., & Lawrence, K. G. (1997). *The Effects of Priming on the Self-Reporting of Perceived Stressors and Strains*. *Source: Journal of Organizational Behavior* (Vol.18).

Moudi, Z., Phanodi, Z., Ansari, H., & Zohour, M. M. (2018). Decisional conflict and regret: Shared decision-making about pregnancy affected by β-thalassemia major in Southeast of Iran. *Journal of Human Genetics*, *63*(3), 309–317.https://doi.org/10.1038/s10038 017-0379-6

Nichols, J. M., Fackler, P. L., Pacifici, K., Murphy, K. D., & Nichols, J. D. (2014). Reducing fatigue damage for ships in transit through structured decision making. Marine Structures, 38, 18–43. https://doi.org/10.1016/j.marstruc.2014.04.002

Nielsen, A. W. M., Kristensen, M. H., Offersen, B. V., Alsner, J., Zachariae, R., & Nielsen, H.M. (2021). Patient-reported outcomes in postmenopausal breast cancer survivors–comparisons with normative data. Acta Oncologica, 60(1), 78–86. https://doi.org/10.1080/0284186X.2020.1834143

Niu, T., Zhang, W., & Xiao, W. (2021). MicroRNA regulation of cancer stem cells in the pathogenesis of breast cancer. *Cancer Cell International*. BioMed Central Ltd. https://doi.org/10.1186/s12935-020-01716-8

Rose, M., Svensson, H., Handler, J., Hoyer, U., Ringberg, A., & Manjer, J. (2020). Patient-reported outcome after oncoplastic breast surgery compared with conventional breast-conserving surgery in breast cancer. *Breast Cancer Research and Treatment*, *180*(1), 247–256. https://doi.org/10.1007/s10549-020-05544-2

Sperlich, S., Arnhold-Kerri, S., & Geyer, S. (2011). What accounts for depressive symptoms among mothers? The impact of socioeconomic status, family structure and psychosocial stress. International Journal of Public Health, 56(4), 385–396. https://doi.org/10.1007/s00038-011-0272-6

Stutts, L. A., Robinson, M. E., McCulloch, R. C., Banou, E., Waxenberg, L. B., Gremillion, H. A., & Staud, R. (2009). Patient-centered outcome criteria for successful treatment of facial pain and fibromyalgia. *Journal of Orofacial Pain*, *23*(1), 47–53. Retrieved from http://www.ncbi.nlm.nih.gov/pubmed/19264035

Swainston, J., Chapman, B., Grunfeld, E. A., & Derakshan, N. (2020). COVID-19 Lockdown and Its Adverse Impact on Psychological Health in Breast Cancer. *Frontiers in Psychology*, *11*, 2033. https://doi.org/10.3389/fpsyg.2020.02033

Thompson, D. I., Sirio, C., & Holt, P. (2000). The strategic use of outcome information. *The Joint Commission Journal on Quality Improvement*, *26*(10), 576–586. https://doi.org/10.1016/S1070-3241(00)26049-5

Vivar, C. G., & McQueen, A. (2005). Informational and emotional needs of long-term survivors of breast cancer. *Journal of Advanced Nursing*. John Wiley & Sons, Ltd. https://doi.org/10.1111/j.1365-2648.2005.03524.x

Wei, C., Wu, M., & Tung, H. (2021). Relationships between health literacy and quality of life among survivors with breast cancer. *International Journal of Nursing Practice*, e12922. https://doi.org/10.1111/ijn.12922

Wenzel, L. B., Fairclough, D. L., Brady, M. J., Cella, D., Garrett, K. M., Kluhsman, B. C., Marcus, A. C. (1999). Age-related differences in the quality of life of breast carcinoma patients after treatment. *Cancer*, *86*(9), 1768–1774. https://doi.org/10.1002/(SICI)1097-0142(19991101)86:9<1768::AID CNCR19>3.0.CO;2-O

Appendix

Appendix A

Table 1

Skewness and Kurtosis

	N	Skewness		Kurtosis	
		Statistics	SE	Statistics	SE
Health Literacy	237	-1.9	0.2	4.9	0.3
Age	252	-0.2	0.2	-0.3	0.3
Obtained					
Physical complaints	247	-1.2	0.2	-0.4	0.3
Psychosocial complaints	247	-0.1	0.2	-1.9	0.3
Emotional and mood problems	247	-0.5	0.2	-1.6	0.3
Fatigue	247	-1.4	0.2	0.1	0.3
Pain complaints	247	-1.0	0.2	-0.8	0.3
Loss in intimacy and sex	247	0.2	0.2	-1.9	0.3
Stress prior periodic controls	247	0.4	0.2	-1.7	0.3
Daily medicine intake	247	0.8	0.2	-1.2	0.3
Side effects of hormone therapy	247	-0.,01	0.2	-1.9	0.3
Risk of recurrence	247	0.01	0.2	-1.8	0.3
Risk of dying	247	0.4	0.2	-1.7	0.3
Desired					
Physical complaints	246	-1	0.2	0.3	0.3
Psychosocial complaints	246	-0.5	0.2	-0.7	0.3
Emotional and mood problems	246	-0.6	0.2	-0.4	0.3
Fatigue	246	-0.7	0.2	-0.4	0.3
Pain complaints	246	-0.5	0.2	-0.7	0.3
Loss in intimacy and sex	246	-0.3	0.2	-1.1	0.3
Stress prior periodic controls	246	-0.1	0.2	-0.9	0.3
Daily medicine intake	246	0.1	0.2	-1.0	0.3
Side effects of hormone therapy	246	-0.6	0.2	-0.8	0.3
Risk of recurrence	246	-0.6	0.2	-0.6	0.3
Risk of dying	246	-2.6	0.2	-0.8	0.3
Valid N (listwise)	232				