

The influence of health literacy, anxiety and education on shared decision making and decisional conflict in older adults, and the mediating role of patient participation: A video observational study

Ruth E. Pel-Littel^{a,b,*}, Bianca M. Buurman^{a,c}, Mirella M. Minkman^{b,d},
Wilma J.M. Scholte op Reimer^e, Jos W.R. Twisk^f, Julia C.M. van Weert^g

^a Department of Internal Medicine, Section of Geriatric Medicine, Academic Medical Centre, University of Amsterdam, Amsterdam, the Netherlands

^b Vilans, Centre of expertise for long-term care, Utrecht, the Netherlands

^c ACHIEVE, Centre of Applied Research, Faculty of Health, Amsterdam University of Applied Sciences, Amsterdam, the Netherlands

^d TIAS School for Business and Society, Tilburg University, Tilburg, the Netherlands

^e Department of Cardiology, Academic Medical Centre, University of Amsterdam, the Netherlands

^f Department of Epidemiology and Biostatistics, Amsterdam UMC, Vrije Universiteit Amsterdam, Amsterdam, the Netherlands

^g Amsterdam School of Communication Research/ASCoR, University of Amsterdam, Amsterdam, the Netherlands

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ABSTRACT

Objective: To explore the relationship between personal characteristics of older adults with multiple chronic conditions (MCCs) and perceived shared decision making (SDM) resp. decisional conflict.

Methods: In a video-observational study (N = 213) data were collected on personal characteristics. The main outcomes were perceived level of SDM and decisional conflict. The mediating variable was participation in the SDM process. A twostep mixed effect multilinear regression and a mediation analysis were performed to analyze the data.

Results: The mean age of the patients was 77.3 years and 56.3% were female. Health literacy ($\beta = 0.01$, $p < .001$) was significantly associated with participation in the SDM process. Education ($\beta = -2.43$, $p = .05$) and anxiety ($\beta = -.26$, $p = .058$) had a marginally significant direct effect on the patients' perceived level of SDM. Education ($\beta = 12.12$, $p = .002$), health literacy ($\beta = -.70$, $p = .005$) and anxiety ($\beta = 1.19$, $p = .004$) had a significant direct effect on decisional conflict. The effect of health literacy on decisional conflict was mediated by participation in SDM.

Conclusion: Health literacy, anxiety and education are associated with decisional conflict. Participation in SDM during consultations plays a mediating role in the relationship between health literacy and decisional conflict.

Practice Implications: Tailoring SDM communication to health literacy levels is important for high quality SDM.

1. Introduction

1.1. Background

To help older adults with multiple chronic conditions (MCCs), defined as having two or more chronic conditions, make choices that fit their individual goals, needs and wishes, shared decision-making (SDM) is a powerful tool [1–3]. SDM is defined as “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options to achieve informed preferences” [4]. Many older patients,

informal caregivers and health professionals still experience barriers to SDM. These barriers include predisposing factors, such as personal characteristics and decision characteristics, as well as interactional, social, organisational and even economic and political context factors [5, 6]. Health professionals find it particularly challenging to involve older adults with MCCs in SDM. This is due to the complexity of interacting conditions [7,8], but also because these patients are more likely to have personal characteristics that complicate participation in SDM. Previous studies have suggested that personal characteristics, such as health literacy, anxiety, frailty, education and age, may influence participation in SDM [9–13]. Patient participation in a consultation is defined as “the

* Correspondence to: Vilans, P.O. Box 8228, Utrecht 3503 RE, the Netherlands.

E-mail address: r.pel@vilans.nl (R.E. Pel-Littel).

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extent to which patients produce verbal responses that have the potential to significantly influence the content and structure of the interaction as well as the health care provider's beliefs and behaviours"[14]. If older adults with MCCs are less involved in SDM, their values and preferences may not be reflected in the decisions made, which might result in reduced SDM outcomes, such as the perceived level of SDM and decisional conflict[14–16]. Perceived level of SDM refers to a patient reported level of SDM: how much a patient feels to be involved in the decision making process[17]. Decision conflict is defined as "personal uncertainty about which course of action to take when choice among competing options involves risk, regret, or challenge to personal life values"[18]. It reflects the degree to which patients express unmet decision-making requirements, including personal uncertainty and associated gaps in knowledge, clarity of values, and support or pressure [19]. Lent et al. [19] found that more decisional conflict was experienced when patients had lower health literacy and poor health[19]. Little is known about the exact influence of personal characteristics on the actual participation of older adults with MCCs in SDM in health care consultations nor on SDM outcomes. To help health professionals optimally engage older adults with MCCs in SDM, we need to better understand how and which personal characteristics influence SDM outcomes. We also need to know whether improving patient participation in SDM during a healthcare consultation can reduce negative effects of personal characteristics on SDM outcomes. The aim of this paper is therefore to (1) describe the relationships between the personal characteristics health literacy, anxiety, frailty, education and age, and SDM outcomes (perceived level of SDM and decisional conflict) and to (2) investigate whether participation in the SDM process during the consultation can mediate the effects of these characteristics on SDM outcomes.

1.2. Defining personal characteristics

Based on our review on barriers and facilitators to SDM in older adults, two other reviews on barriers and facilitators to SDM, we identified the personal characteristics health literacy, frailty, education and age as potential variables that influence SDM in older patients[9–13]. We also included anxiety as a characteristic, however, it did not emerge from these reviews. Anxiety is a poorly understood phenomenon in relation to health care communication, but we expect it to have an influence on participation in shared decision making. Although there may be more personal characteristics that influence SDM in this group, we choose the ones that emerged most clearly in these reviews and that we were able to analyze in our existing dataset. For each characteristic we give a definition, describe its prevalence among older adults with MCCs and explain why this characteristic might influence SDM participation and outcomes.

1.2.1. Health literacy

Health literacy is defined as the ability to obtain, process, and understand the basic health information and services needed to manage one's health and make appropriate health decisions[12]. Low health literacy is especially prevalent among older adults, with low rates of health literacy ranging from 30 - 68%[12,20,21]. Low health literacy is associated with poor health[16] and with more MCCs[12]. Additionally, adults with low health literacy are more often acutely admitted to the hospital[12,21]. Some studies suggest that lower health literacy is associated with a higher chance of nonadherence as a result of a lack of understanding of the given instructions[20]. Low health literacy among older adults is also associated with a poor SDM ability[12]. Older adults with MCCs who lack the ability to understand and communicate health information may have trouble participating in parts of the SDM process, such as understanding the risks and benefits of procedures, which might lead to lower levels of perceived SDM and decisional conflict[12,13]. To this purpose we investigated the relation between health literacy and participation of older adults in the SDM process in relation to outcomes

as the level of perceived SDM and decisional conflict.

1.2.2. Anxiety

The American Psychological Association defines anxiety as an emotion characterized by feelings of tension, worried thoughts, and physical changes like increased blood pressure [22]. Anxiety is highly prevalent among older adults with MCCs (7–58%)[9,10,23]. Anxiety is associated with considerable distress, impairment of quality of life, disability, poor health, increased mortality and increased use of health services[10,24,25]. Common anxiety symptoms are nervousness, restlessness, being tense and feelings of danger or panic. In a patient-centred care approach, alleviation of fear and anxiety is seen as an important indicator of quality and safety[26]. Anxiety may impact cognitive focus, energy and motivation and is expected to affect adults' willingness and ability to decide to undergo medical treatment, possibly resulting in the exacerbation of illness or incorrect diagnoses[10]. When there is a high level of anxiety, older adults may not be able to process all relevant information to make the best decision[27]. Anxiety may leave the patient wanting to surrender decision making to the clinician[28]. Some studies report that providing knowledge, a common intervention to empower adults, may have a contradictory effect in adults with anxiety [28–30]. The effect of anxiety on participation in SDM, the perceived level of SDM and decisional conflict is poorly understood, but we expect that older adults with high levels of anxiety are less likely to participate in SDM which may result in lower perceived levels of SDM and more decisional conflict. To this purpose we investigated the relation between the participation of older adults with anxiety in the SDM process in relation to outcomes such as the level of perceived SDM and decisional conflict.

1.2.3. Frailty

Frailty is defined as "a clinical state in which there is an increase in an individual's vulnerability for developing increased dependency and/or mortality when exposed to a stressor. Frailty can occur as the result of a range of diseases and medical conditions"[31]. Frailty is associated with the loss of functional independence, a higher risk of falling, reduced quality of life and higher hospitalization and mortality[32–35]. It is estimated that approximately 20–30% of adults over 75 years are frail, and women are at higher risk for frailty than men[33]. While frailty is often linked with advancing age, it is more closely tied to biological aging rather than chronological aging. A person's chronological age does not necessarily mirror their degree of frailty. For frail adults, balancing the benefits and harms of a treatment is important because resilience, the ability to rebound in difficult situations[36], is often low and choices of treatment, such as surgery, can have major consequences on care needs due to, sometimes permanent functional loss[11]. Faced with complex health decisions participating in SDM is of the utmost relevance to frail adults[11]. However, due to their frail condition, frail adults might not be able to participate fully in SDM. In several studies older patients reported that a frail condition affected their ability to understand information[37–39] and to participate in decision making. [39,40]. In order to get a better insight into SDM with frail older adults we investigated the relation between the participation of frail older adults in the SDM process in relation to outcomes as the level of perceived SDM and decisional conflict.

1.2.4. Education

In general, higher levels of education are often associated with higher preferences for SDM[41–43]. It is assumed that higher levels of education increase patients' confidence to participate in SDM and that more educated patients are more motivated to participate in SDM[41]. On the other hand, the impact of education in older adults is complex, for example, because in the past, the educational opportunities have been different for men and women, and women have historically had less access to education than men. As a result, educational attainment is not the same as intelligence. In addition, education is sometimes seen as

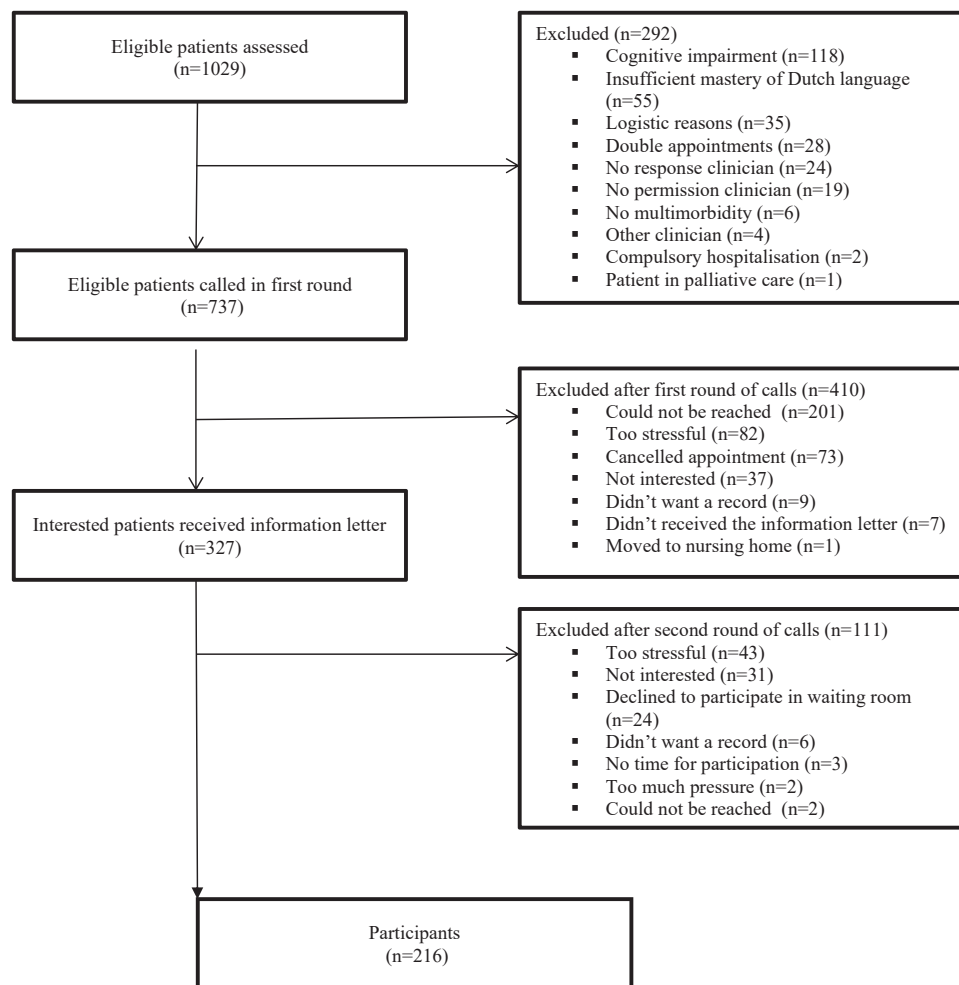


Fig. 1. Flowchart of the inclusion.

a proxy for health literacy. As health literacy has been defined as a set of skills, this concept includes more skill-based indicators than education alone (e.g., reading ability, general literacy, experience of healthcare) [44,45]. To gain more insight into the separate role of education, we wanted to investigate the actual influence of older adults' level of education on participation in the SDM process in relation to outcomes such as the level of perceived SDM and decisional conflict.

1.2.5. Age

Ageing influences the way and speed with which adults process information regarding their illness and treatment [46,47]. Mata [47] found that older adults search for less information and take longer to process it, and that they also rely on simpler and less effortful strategies. Health professionals encourage older adults to participate in SDM less often than middle-aged patients and older patients find themselves less assertive when it comes to participating in SDM [27]. Although older adults prefer involvement in their care, they see this involvement more in the relationship and in receiving information than in actual participation in SDM [48]. In this study we investigated the effect of age differences on participation in the SDM process and in relation to outcomes such as the level of perceived SDM and decisional conflict.

1.3. The current study

To summarize, we discussed the possible influence of the personal characteristics health literacy, anxiety, frailty, education and age on participation in the SDM process and, consequently, the perceived level

of SDM and decisional conflict. To address our goals we empirically test which of these personal characteristics contribute to outcomes of SDM and investigate whether participation in the SDM process during consultation can mediate these effects.

2. Methods

2.1. Design

This study is a retrospective analysis of data acquired in two video observational studies among geriatric patients visiting the geriatric outpatient clinic of either the Amsterdam Medical Center or the Medical Center Slotervaart, two hospitals in Amsterdam, the Netherlands, between 2016 and 2018.

The first video observational study aimed to observe the level of SDM in conversations between older patients with MCCs, their informal caregivers and the geriatricians [49]. The results of this study showed that the level of SDM among geriatricians, measured with the Observer Option^{MCC} was relatively high (39.3, range 0 - 100) compared to levels of SDM in other studies: the mean OPTION score of 33 studies in the review of Couet et al. (2015) was 23 (range 0–100) [50]. In order to further raise the SDM levels, the participating geriatricians were trained in SDM and patients were invited to participate in SDM by means of a preparatory tool that they could fill in prior to the conversation. The key elements of the preparatory tool include an explicit invitation to participate in SDM, nomination that the patient's own knowledge is valuable, invitation to form a partnership with the geriatrician and

encouragement to share information about daily and social functioning and personal goals [51]. However the implementation of the preparatory tool was at that time unsuccessful, it was only used in 11% of the consultations [51]. A second video observational study aimed to investigate whether the levels of SDM in conversations between older patients with MCCs, their informal caregivers and the geriatricians were higher compared to the first study. The results showed no significant differences between the first and the second video observational study on the perceived level of SDM, decisional conflict and participation in SDM (overall Observer Option^{MCC} score) [52].

Since there were no significant differences in these outcomes between the first and the second video observational study, data of both studies were included in this retrospective analysis.

2.2. Participants

The participants in this analysis were 213 geriatric patients who visited the outpatient clinic of one of the participating hospitals. Typically, geriatric patients present with MCCs and the consequences they cause in daily life, such as falls, mobility problems, malnutrition, depression, delirium, dizziness and reduced independence. A geriatric consultation usually includes a comprehensive geriatric assessment and decisions on additional diagnostics, medication, lifestyle adjustments and referral to other health professionals in the hospital (another specialist) or to primary care (e.g. case manager, physiotherapist, psychologist). The inclusion criteria for this study were: 1) sufficient mastery of the Dutch language, 2) a life expectancy of more than 3 months, and 3) not having a severe stage of dementia (MMSE ≤ 15) according to the medical file. Fig. 1 presents the flow chart of the study.

2.3. Procedure

Eligible patients received an information letter. The consultations of the included patients were video recorded to enable rating by different observers. The observers were not present during the consultation. In addition, data regarding the personal characteristics and the outcome variables were collected through pre- and post-consultation questionnaires. The pre-consultation questionnaire was sent out by post prior to the consultation, the post-consultation questionnaire was completed in the waiting room immediately after the consultation. The geriatricians completed a baseline questionnaire and a short post-consultation questionnaire. Written informed consent was obtained from all participating patients and geriatricians. Further details on the procedure are published elsewhere [49,51].

2.4. Measurements

2.4.1. Personal characteristics

- Health literacy was measured with the Short Assessment of Health Literacy in Dutch (SAHL-D22) [53,54]. Participants were asked to select the correct meaning of each word out of three multiple choice options. The total score ranged from 0 to 22, with higher scores indicating higher health literacy.
- Anxiety was measured with the short Spielberger State-Trait Anxiety Inventory (STAI). This self-report instrument is mostly used in clinical settings to measure anxiety at the actual moment (state anxiety) and anxiety in general (trait anxiety) [55,56]. In this study we used the STAI-6 to measure state anxiety. Therefore, only the state anxiety questions were used. Answers to the STAI-6 were scored on a 4-point Likert scale ranging from 'not at all' to 'very much'. The total scores ranged from 20 to 80, with a score of 44 or higher considered the cut-off for clinical anxiety levels [57–60].
- Frailty was measured using the Groningen Frailty Indicator (GFI). The GFI is a validated self-reported screening instrument consisting of 15-items [61]. The total score ranged from 0 to 15, with a score of



Fig. 2. Observer OPTION^{MCC}.

four or higher considered the cut-off point for frailty [61]. Higher scores on the GFI indicated higher frailty levels.

- Education was divided into the lower educational level (primary school or less), the middle educational level (lower vocational, preparatory secondary vocational, intermediate secondary vocational education, senior secondary vocational and university preparatory vocational education) and the higher educational level (higher vocational education and university).

In addition gender, comorbidities and polypharmacy [52] were measured as control variables.

2.4.2. Mediating variable

The level of participation in the SDM process during the consultation was measured with the Observer OPTION^{MCC} [62]. The Observer OPTION^{MCC} was developed to measure triadic decision making in older adults with MCCs (Fig. 2). The scale consists of 7 items and measures the competences of geriatricians and the level of participation among older adults with MCCs and their informal caregivers. The items are: 1: Goal talk (identify the discussion partner, identify the patient's values and the goals of care), 2: Option Talk (explaining that there are more options), 3: Team Talk (Support deliberation, forming a partnership), 4: Option Talk (information about options) 5: Decision Talk (eliciting preferences), 6: Decision Talk (integrating preferences), and 7: Evaluation talk (evaluating the SDM process, preparing the treatment plan). For the current study, we used the mean observer OPTION^{MCC} patient scores. The level of participation of the patients was rated on three levels: (0) no participation, (1) responsive participation and (2) active participation. The total scores ranged from 0 to 2.

2.4.3. Outcome variables

1. The *perceived level of SDM* was measured with the patient reported experience measure (PREM): CollaboRATE. CollaboRATE assesses three core SDM tasks: (1) explanation about health issues, (2) elicitation of patient preferences and (3) integration of patient preferences into decisions. The responses to each item ranged from 0 (no effort was made) to 9 (every effort was made). CollaboRATE scores

Table 1
Participant Characteristics.

	N ^a = 213 77.3 (7.9)
Mean age in years (SD)	
Female sex (n, %)	120 (56.3)
Informal caregiver present (n,%)	133 (62.4)
Polypharmacy ^b (≥ 4) (n,%)	137 (64.3)
Comorbidity ^c (CCI) ^e (mean, SD)	1.9 (1.9)
Health literacy (SAHL-D22) ^d (mean, SD)	11.8 (6.9)
Anxiety (STAI) ^e pre-consultation	11.1 (4.2)
Frailty (GFI) ^f mean, SD	4.3 (2.5)
Level of education	
Low (n, %)	31 (15.2)
Middle (n, %)	118 (57.8)
High (n, %)	55 (27.0)

^a Three patients were excluded after analysis, due to too much missing data (see flow chart) and n varies slightly due to missing data

^b Polypharmacy: use of > 4 different medications

^c Comorbidity: CCI (A higher CCI-score (>5) is associated with higher morbidity and mortality)

^d Health literacy: SAHL-D22 (score 0-22; a higher score indicates higher health literacy)

^e Anxiety: STAI-6 (score 6-24; a higher score indicates more anxiety)

^f Frailty: GFI (score 0 - 15; score > 4 indicates frailty)

are calculated as the proportion of participants who report a score of nine on each of the three CollaboRATE questions[17,63,64].

2. **Decisional Conflict** was measured with the Decisional Conflict Scale (DCS), a self-administered questionnaire developed by O'Connor et al. [65–67]. The DCS consists of 16 items clustered on 5 subscales: 'information', 'clarification of values', 'support', 'uncertainty' and 'effective decision'. All the items are measured on a 5-point Likert scale[65]. The answer options on this scale vary from 'strongly agree' (0) to 'strongly disagree' (4). For this study we used the total DCS score, which varies between 0 (no decisional conflict) and 100 (extremely high decisional conflict)[65]. A lower total score indicates less decisional conflict. A total score lower than 25 is associated with effectively doing what was decided. A total score greater than 37.5 is associated with decision delay and feeling unsure about the implementation of the decision[65,67].

2.4.4. Statistical analysis

Linear mixed model analyses were used to analyze 1) the

relationships between personal characteristics, and SDM outcomes (the perceived level of SDM and decisional conflict). 2) the relationships between personal characteristics and the mediation variable (i.e. participation in the SDM process). First, these relationships were analyzed separately for each personal characteristic and second, these relationships were analyzed in a multivariable model in which all personal characteristics were entered together. Finally, a mediation analysis was performed to evaluate the mediating influence of participation in the SDM process in the relationship between personal characteristics and SDM outcomes. Therefore, participation in the SDM process was added to the linear multivariable mixed model analysis regarding the relationship between personal characteristics and SMD outcomes. The influence of the mediating variable was evaluated by comparing the regression coefficient of the model without the mediation variable with the regression coefficient of the model with the mediation variable. However, mediation analyses were only performed when there was a significant relationship between a personal characteristic and an SMD outcome.

Mixed model analysis was used to take into account the correlated observations within departments and all analyses were performed with Stata (version 14).

3. Results

3.1. Response

During the study period, 1029 older adults visited one of the two hospitals for a geriatric consultation with a geriatrician of whom 216 (21%) participated in the study (see Fig. 1). We excluded three patients because they had too much missing data, leaving 213 participants for analysis. We found no significant difference in age or gender between the participating patients and the nonresponding patients.

3.2. Baseline characteristics

Table 1 summarizes the baseline characteristics of the patients. The mean age of the patients was 77.3 years (SD 7.9). The majority of participating patients were female (56.3%). The mean health literacy of the patients was 11.8 (SD 6.9), indicating moderate health literacy levels. The mean STAI-6 score was 11.1 (SD 4.2), indicating a moderate level of anxiety and the mean frailty score of the patients was 4.3 (SD 2.5), indicating frailty. Of the participating patients, 31 (15.2%) had a

Table 2
The relationship between personal characteristics and the perceived level of SDM and decisional conflict.

Perceived level of SDM ^a		Univariable analysis			N ^b = 155		
	N ^{b,d}	B	95% CI	p-value	Multivariable analysis ^c		
					B	95% CI	p-value
Health Literacy	159	-.05	(-.19;.08)	.46	.01	(-.17;.15)	.92
Anxiety	159	-.32	(-.56;-.08)	.01**	-.26	(-.53;.01)	.06
Frailty	161	-.38	(-.75;-.01)	.04*	-.25	(-.66;.17)	.24
Education	164	-2.20	(-4.32;-.09)	.04*	-2.43	(-4.91;.042)	.05
Age	164	.01	(-.10;.12)	.85	.01	(-.10;.13)	.83
Decisional Conflict ^c		Univariable analysis			N ^b = 137		
	N ^{b,d}	B	95% CI	p-value	Multivariable analysis		
					B	95% CI	p-value
Health Literacy	140	-.47	(-.91;-.03)	.04*	-.70	(-1.19; -.20)	.01*
Anxiety	140	1.29	(.53;2.06)	< .001***	1.19	(.38; 2.01)	< .001**
Frailty	141	.88	(-.29;2.04)	.14	-.01	(-1.23; 1.21)	.99
Education	144	4.05	(-3.43;11.53)	.29	12.12	(4.40; 19.84)	< .001**
Age	144	.20	(-.18;.58)	.31	.04	(-.31;.38)	.83

^a SDM: CollaboRat% patients that have a Topscore, a higher % indicates a higher level of SDM

^b N varies due to missing data ^c Multivariable analysis: multivariable linear mixed model analyses in which all personal characteristics were analyzed together ^d N for univariable analysis ^e Decisional Conflict Scale: DCS: (score 0 - 100) a higher score indicates a higher level of decisional conflict

* <.05 ** < .01 *** <.001

Table 3

The relationship between personal characteristics and observed participation in SDM.

Variable		univariable analysis			multivariable analysis ^a		
Health literacy		N = 190			N = 183		
Anxiety	Mean OPTION ^b	B	95% CI	p-value	β	95% CI	p-value
		.02	(.01;.03)	< .001 ***	.02	(.01;.03)	< .001 ***
Frailty	Mean OPTION	N = 188			N = 183		
		β	95% CI	p-value	β	95% CI	p-value
Education	Mean OPTION	.01	(-.01;.02)	.58	.01	(-.01;.03)	.60
		β	95% CI	p-value	β	95% CI	p-value
Age	Mean OPTION	-.01	(-.04;.02)	.42	-.01	(-.04;.02)	.65
		β	95% CI	p-value	β	95% CI	p-value
	Mean OPTION	.11	(-.05;.27)	.19	-.06	(-.24;.12)	.53
		β	95% CI	p-value	β	95% CI	p-value
	Mean OPTION	-.01	(-.02;.00)	.03 *	.00	(-.01;.00)	.26
		β	95% CI	p-value	β	95% CI	p-value

^a Multivariable analysis: multivariable linear mixed model analyses in which all personal characteristics were analyzed together^b This table presents only mean OPTION scores, in the supplemental files the full table of alle OPTION item scores is included * <.05 ** <.01 *** <.001**Table 4**

The mediating influence of participation in the SDM process in the relationship between personal characteristics and the perceived level of SDM.

Perceived level of SDM	N = 155 VARIABLE					
	Education			Anxiety		
	β	95% CI	p-value	β	95% CI	p-value
Mean OPTION ^a	-2.23	(-4.44; -.02)	.05	-.33	(-.57; -.09)	.01 *

^a This table presents only mean OPTION scores, in the supplemental files the full table of alle OPTION item scores is included

* <.05 ** <.01 *** <.001

low education level.

3.3. Primary findings

The influence of personal characteristics on the perceived level of SDM and decisional conflict are depicted in Table 2. The multivariable analysis shows that anxiety ($\beta = .26$, $p = .06$) and education (high education level versus middle and lower education level) ($\beta = 2.43$, $p = .05$) had marginally significant effects on the perceived level of SDM, indicating that patients with less anxiety and a lower education perceived the SDM process to be better. Health literacy ($\beta .01$, $p = .92$), frailty ($\beta = .25$, $p = .24$) and age ($\beta .01$, $p = .83$) had no significant effect on the perceived level of SDM. Health literacy ($\beta = .70$, $p = .01$), anxiety ($\beta 1.19$ $p < .001$) and education ($\beta 12.12$, $p < .001$) had a significant effect on decisional conflict, indicating that patients with lower health literacy, more anxiety and higher education perceived more decisional conflict. Frailty ($\beta = .01$, $p = .99$) and age ($\beta .04$, $p = .83$) had no significant effect on decisional conflict.

Table 3 shows the relationship between each personal characteristic

Table 5

The mediating influence of participation in the SDM process in the relationship between personal characteristics and decisional conflict.

Decisional Conflict	N = 137 VARIABLE								
	Education			Health Literacy			Anxiety		
	β	95% CI	p-value	β	95% CI	p-value	B	95% CI	p-value
Mean OPTION ^a	11.71	(4.15; 19.27)	.00 **	-.47	(-.97;.03)	.07	1.28	(.57; 2.00)	.00 **

^a This table presents only mean OPTION scores, in the supplemental files the full table of alle OPTION item scores is included

* <.05 ** <.01 *** <.001

and observed participation in the SDM process. The multivariable analysis shows that health literacy ($\beta .02$, $p < .001$) was significantly related to observed participation in the SDM process (mean OPTION^{MCC}), indicating that people with higher levels of health literacy participated more in the SDM process. Although the univariable analysis shows that age ($\beta = .01$, $p = .03$) was significant related to observed participation in the SDM process (mean OPTION^{MCC}), this relationship was not significant in the multivariable analysis.

Table 4 shows that there was no meaningful mediating influence of participation in SDM on the relationship between personal characteristics and the perceived level of SDM. Table 5 shows that the effect of health literacy on decisional conflict was mediated by participation in the SDM process, i.e. the regression coefficient for health literacy in the model without the mediation variable was much higher than the regression coefficient for health literacy in the model with the mediation variable This finding means that the effect of health literacy on decisional conflict partly goes through participation in the SDM process.

4. Discussion and conclusion

4.1. Discussion

The aim of this study was to explore the possible influence of the personal characteristics health literacy, anxiety, frailty, education and age on the perceived level of SDM and decisional conflict and to investigate whether patient participation in the SDM process during a consultation mediates these outcomes. We found that anxiety and education marginally affect the outcomes of SDM as expressed by the perceived level of SDM and that health literacy, anxiety and education affect the outcomes of SDM as expressed by decisional conflict. Although age is not related to these SDM outcomes, higher age leads to less participation in SDM. Furthermore, we found that the effect of health literacy on decisional conflict was mediated by participation in the SDM communication during consultation.

Previous studies have focused on the relation between low health

literacy and SDM outcomes regarding the use of decision aids, but comparing our results to the results of those studies is difficult because our research focused on actual participation in the SDM process during a consultation. The reviews by McCafferty et al. [68] and Stacey [69] et al. provide evidence that lower literacy is related to higher decisional conflict in the context of using patient decision aids [68,69]. Additionally, these reviews indicate that adults with low literacy levels have a lower desire to participate in SDM [68,69]. By observing how older adults participated in the SDM process, we were able to reveal new insights for older adults with low health literacy. We found that if more participation in the SDM process was observed during the consultation, then it had a positive effect on the level of decisional conflict in older adults with lower levels of health literacy. The interventions described in the literature to promote the perceived level of SDM and to reduce decision conflict in these specific groups, are characterized by the use of plain language and are concise, simple and tailored [70]. However, these interventions mainly target patient decision aids, videos and patient training (pre-consultation). These interventions can help patients to become more active participants in their health care, but they are mostly designed for use outside the meeting with the health professional. Future research should explore how health professionals can improve older adults' participation in the SDM process during a consultation. During the actual consultation, health professionals can improve their skills to identify low health literacy earlier and adapt their communication accordingly, for example by using plain language and asking the patient to repeat what they have learned ("teach-back" method) to make sure they have understood the decision and what it means for them. This may increase their perceived level of SDM and reduce their decisional conflict, particularly for those with low health literacy. Therefore, we recommend to assess health literacy before SDM, to enable health professionals to adapt their communication. Although there exist numerous tools to assess health literacy, the challenge is to find short, usable assessment tools for daily clinical practice, such as the Single Item Literacy Screener [71,72].

In line with what we expected to find, patients with higher levels of anxiety perceive less SDM and experience more decisional conflict. We found in the literature that adults with anxiety would have more difficulty participating in SDM due to the impact of anxiety on cognitive focus, energy and motivation [10]. We anticipated, therefore, that anxiety would be related to less participation in SDM, but this hypothesis was not confirmed in our analysis. Further research is needed to explore which components of participation in the SDM process should be addressed to reduce decision conflict and increase perceived levels of SDM among older adults with anxiety.

In the current study we did not find an association between frailty and participation in the SDM process and SDM outcomes. This finding might be explained by the broad concept of frailty, allowing considerable heterogeneity in the population of frail patients. Furthermore, on the one hand we expected that the experience that frail older adults have of living with chronic conditions would allow them to better express their goals and preferences and thus participate in SDM [11]. On the other hand the complexity of the situation of frail adults, such as the aspect of MCCs, may hinder their participation in SDM [73,74]. This situation might lead to mutually cancelling effects making it seem that there are no effects.

We found in our study that higher education led to less perceived SDM and more decisional conflict. This effect might be explained by the fact that more highly educated older adults are more aware of the complexity of the decisions they face. The literature is ambiguous on this issue. Some studies confirm this relationship [75], but other studies report that a higher level of education is associated with higher levels of perceived SDM [76] and lower decisional conflict. However, these studies targeted other populations, psychiatric patients and younger adults, and thus are not fully comparable to our study. We hypothesized that more highly educated adults would participate more in SDM compared to less educated adults, but we did not find this relation. An

explanation for this finding could be that for older adults, the timing of their education is usually decades ago which decreases the effect of education, depending on how one's life has developed. Since we found a stronger effect of health literacy, this finding may be a more important factor to take into account than education.

Although age was not related to the perceived level of SDM and decision conflict, we found a direct relationship between age and participation in SDM in the univariable analysis. The older people are, the less they participate in SDM. However, this relationship was not significant in the multivariable analysis, probably due to the relationship between age and health literacy. Additionally, this relationship does not seem to affect SDM outcomes. A possible explanation may be that in many cases, and possibly in more cases when people are very old, informal caregivers may have offset the effect of 'very old age' by being more active in the SDM process. A recent study (Dijkman, 2022) showed that patients > 85 were more likely to have adult children as informal caregivers than patients < 85, who were more likely to have partners as informal caregivers. The adult children were more active in the SDM discussion than the partners. It would be interesting to further explore how SDM participation differs between the 'oldest old' and the 'old', and how informal caregivers (and their type) mediate this difference. However, due to the limited sample size, it was not possible to analyze this in the current study. Few studies focus on the participation of older adults in SDM, and most of these studies focus on preferences for SDM, not on actual participation in SDM, which was the focus of our study [1, 27,77,78]. However, Bynum et al. (2015) reported on engaging the very old (80+) in decision making and found that very old adults participate to some degree in SDM, and that they "have the potential to be active participants in decision-making" [79]. This process requires skills from health professionals to anticipate the barriers very old adults experience in SDM.

4.2. Strengths and limitations

Although we found no significant differences between participants and non-participants in regard to age and gender, the sample could be biased on other characteristics, such as health literacy. However, we could not obtain any data on health literacy among the non-participants. Due to the frailty of the patient population and the sample size, we were limited in the number of characteristics that could be analyzed. We, therefore, focused on, to our knowledge, the most relevant personal characteristics: health literacy, anxiety, frailty, education and age. However, other characteristics such as impaired cognition, emotional wellbeing or gender, may also be associated with SDM outcomes and might be mediated by participation in SDM. Impaired cognition may influence how geriatric patients participate in shared decision making. However, we could not include this factor in our analysis, as we only had information on whether patients had a MMSE score < 15 (indicating moderate or severe dementia) before the consultation. We excluded these patients from the study. In this study we did not analyze whether there was a relation between the type of decision, personal characteristics and participation in SDM. It could be argued that a decision about surgery has other impacts on participation in SDM compared to a decision about a small change in medication regime. Finally, in this study we focused solely on the personal characteristics of older adults. It would be interesting to also study in which way personal characteristics of health professionals influence their participation in SDM.

4.3. Conclusions

To our knowledge no similar studies that have found that health literacy, anxiety and education of older adults with MCCs are related with their perceived level of SDM and decisional conflict. By observing how older adults participated in the SDM process, we were able to reveal new insights for older adults with lower health literacy. We found that if more SDM communication takes place in the consultations, then it had a

positive effect on the level of decisional conflict for older adults with lower health literacy.

4.4. Practice Implications

Health professionals can enhance their ability to identify low health literacy early and adjust their communication accordingly. For instance, they can use plain language and employ the “teach-back” method, asking patients to repeat what they’ve learned to ensure comprehension of decisions and their implications. Additionally, we recommend assessing health literacy before SDM to empower older adults with low health literacy to participate in SDM. Concise assessments such as the Single Item Literacy Screener, suitable for everyday clinical practice, facilitate this. Further research is recommended for SDM with anxious older people so that they experience less decisional conflict.

Ethics Committee approval

The requirement to obtain approval was waived by the institutional Review Board of the AMC (W16_107#16.125, W17_284#17.336). Written informed consent was obtained from all patients, informal caregivers and geriatricians. All methods were carried out in accordance with relevant guidelines and regulations.

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Author statement

All authors have read and approved of the final manuscript. Study concept and design: RP, JW, BB. Acquisition of data: RP. Analysis and interpretation of data: RP, JW, BB, JT. Preparation and critical revision of the manuscript: RP, BB, JT, MM, WSR, JW.

CRedit authorship contribution statement

Ruth E. Pel-Littel: Writing – review & editing, Writing – original draft, Funding acquisition. **Bianca M. Buurman:** Supervision, Methodology, Funding acquisition. **Mirella M. Minkman:** Supervision, Methodology. **Wilma J.M. Scholte op Reimer:** Supervision. **Jos W.R. Twisk:** Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation. **Julia C.M. van Weert:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Funding acquisition, Formal analysis, Conceptualization.

Declaration of Competing interest

The authors declare that they have no competing interests.

Data Availability

The minimal anonymized data set of this study has been uploaded to fig share; https://figshare.com/articles/dataset/_b_Dataset_for_The_influence_of_health_literacy_anxiety_and_education_on_shared_decision_making_with_older_adults_mediated_by_patient_participation_a_video_observational_study_b_/25249870.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.pec.2024.108274](https://doi.org/10.1016/j.pec.2024.108274).

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