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Shifting from “What is the matter?” to “What matters to you?”

Shared decision making for older adults with multiple chronic conditions and their informal caregivers

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Publication date

2020

Document Version

Other version

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Citation for published version (APA):

Pel-Littel, R. E. (2020). *Shifting from “What is the matter?” to “What matters to you?”: Shared decision making for older adults with multiple chronic conditions and their informal caregivers*. [Thesis, fully internal, Universiteit van Amsterdam].

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Health literacy, anxiety and education influence shared decision making for older adults with multiple chronic conditions: the DICO-study



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Submitted

Abstract

Introduction: We explored the influence of the personal characteristics of older adults with multiple chronic conditions (MCCs) on perceived shared decision making (SDM) and decisional conflict, and investigated whether participation in SDM can mediate these SDM outcomes.

Methods: Two hundred-sixteen older adults with MCCs visiting the geriatric departments of two hospitals participated in a video-observational study. Data were collected on health literacy (measured with SAHL-D22), anxiety (STAI-6), frailty (GFI), education and age. The main outcomes were perceived level of SDM (CollaboRATE) and decisional conflict (Decisional Conflict Scale). The mediating variable was participation in the SDM process during consultations with geriatricians, measured as patients' OPTION^{MCC} score. A twostep mixed effect multilinear regression and a mediation analysis were performed to analyze the data.

Findings: The mean age of the patients was 77.3 years and 56.3% were female. Health literacy (β .01, $p < .001$) was significantly related to 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. Furthermore, 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.

Conclusions: Health professionals need to be aware of personal characteristics of older adults with MCC, since health literacy, anxiety and education are associated with decisional conflict. Moreover the effect of health literacy on decisional conflict is mediated by participation in SDM communication during consultation. This indicates that tailoring SDM communication to health literacy levels is important for high quality SDM communication and, consequently, better outcomes.

Introduction

Shared decision making (SDM) requires capacity from both health professionals and patients. Many health professionals find it challenging to involve older adults with multiple chronic conditions (MCCs) in SDM^{1,2}, not only due to the complexity of interacting conditions^{3,4}, but also because there is a wide variation in both older adults and professionals in the way they are able to participate in SDM. Previous studies have suggested that the personal characteristics of patients, such as health literacy, anxiety, frailty, education and age, may influence the SDM process and, consequently, patient outcomes⁵⁻⁹. However, little is known about the exact influence of these characteristics on the actual participation of older adults with MCCs in SDM in health care consultations nor on SDM outcomes. Patient participation in a consultation is defined as ‘the 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’¹⁰. When older adults participate more actively in the SDM process during health care consultations, better outcomes can result, such as a better perceived level of SDM and less decisional conflict¹¹⁻¹³. Perceived level of SDM refers to a patient reported level of SDM¹⁴. 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”¹⁵. The “Dynamic model for SDM in frail older patients”, a six-step conversation model for SDM, proposes an approach to enhance participation in SDM during consultation by discussing preferred decision roles and decision capacities, continually engaging the older adult and his/her informal caregiver in dialogue, observing the older adults’ reactions and evaluating the decision making process¹⁶. However, to help health professionals engage older adults with MCCs optimally in SDM, we need to gain a better understanding of how and which factors influence SDM outcomes and whether these effects can be mediated by participation in SDM during a healthcare consultation. Additionally, older adults can be empowered in a personalized way if it can be demonstrated that this process leads to higher levels of perceived SDM and less decisional conflict.

The aim of this paper is 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.

Theoretical framework

Based on previous literature we were primarily interested in the personal characteristics health literacy, anxiety, frailty, education and age as potential variables that influence SDM.

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 decisions⁸. Low health literacy is especially prevalent among

older adults, with low rates of health literacy ranging from 30 - 68%^{8, 17, 18}. Low health literacy is associated with poor health¹⁶ and with more MCCs⁹. Health literacy is even more affected when older adults experience cognitive decline, leading to increased difficulty making health choices^{9, 19}. Additionally, adults with low health literacy are more often acutely admitted to the hospital^{8, 18}. 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 instructions¹⁷. Low health literacy among older adults is also associated with a poor SDM ability⁸. 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^{8, 9}. 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.

Anxiety

The prevalence of anxiety symptoms ranges from 7-58% among older adults^{5, 20}. Anxiety is highly prevalent among older adults with MCCs^{5, 6}. Anxiety is associated with considerable distress, impairment of quality of life, disability, poor health, increased mortality and increased use of health services^{6, 21, 22}. 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 safety²³. 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 diagnoses⁶. When there is a high level of anxiety, older adults may not be able to process all relevant information to make the best decision²⁴. Anxiety may leave the patient wanting to surrender decision making to the clinician²⁵. Some studies report that providing knowledge, a common intervention to empower adults, may have a contradictory effect in adults with anxiety²⁵⁻²⁷. 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.

Frailty

Frailty is widely recognized as a common exponent of biological age^{28, 29}. Although a universally accepted definition of frailty is lacking, more recent studies have shifted from a physical definition towards a more multidimensional definition of frailty that includes psychological and social domains^{28, 30}. In this view, frailty can be defined as "a dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological, social), which is caused by the influence of a range of variables and which increases the risk of adverse outcomes."³¹ It is estimated that approximately 20-30% of

adults over 75 years are frail, and women are at higher risk for frailty than men³⁰. Frailty is associated with the loss of functional independence, a higher risk of falling, reduced quality of life and higher hospitalization and mortality³⁰⁻³³. For adults who are frail, balancing the benefits and harms of a treatment is important, since resilience is often low. Treatment choices, such as surgery may have consequences for care giving needs due to, sometimes indefinite, functional loss⁷. Faced with complex health decisions a dialogue about the goals of care and quality of life is of the utmost relevance to frail adults⁷. However, due to their frail condition, frail adults might not be able to participate fully in SDM. When a patient is very ill, their ability to understand information³⁴⁻³⁶ and to participate in decision making is affected^{36, 37}. On the other hand, previous experiences of frail older adults in dealing with conditions and decision making acts as a facilitator to participate in SDM^{1, 35, 38}. 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.

Education

In general, higher levels of education are often associated with higher preferences for SDM³⁸⁻⁴⁰. It is assumed that a higher level of education increases patient confidence to participate in SDM and that higher educated patients are more motivated to participate in SDM³⁸. In order to gain more insight into this, we wanted to investigate the actual influence of the educational level of older adults on participation in the SDM process in relation to outcomes such as the level of perceived SDM and decisional conflict.

Age

Ageing influences the way and speed with which adults process information regarding their illness and treatment^{41, 42}. 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 SDM²⁴. 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 SDM⁴³. 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.

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.

Methods

Design

This video observational study with surveys was part of the “**D**ecision making **I**n **C**omplex **O**ld populations (DICO)” study. This study was carried out at geriatric outpatient clinics in two hospitals in Amsterdam, 1) the Academic Medical Center (AMC) and 2) the Medical Centre Slotervaart, a non-academic teaching hospital (MC SLV), between 2016 and 2018. The Institutional Review Board of the AMC waived the requirement to obtain approval for this study (W16_107#16.125, W17_284#17.336).

Participants

The participants in this study were 216 geriatric patients divided in two groups (usual care and intervention) who visited the outpatient clinic of one of the participating hospitals between April 2016 and June 2017 and between Oct 2017 and June 2018. The intervention group received a preparatory tool, and the geriatricians received SDM training. Since there were no significant differences in perceived level of SDM and decisional conflict and participation in SDM between the usual care and the intervention groups, both groups were included in this study (Pel-Littel RE, Buurman BM, van de Pol MH, Twisk JWR, Tulner LR, Minkman MM, et al. Effects of the SDM^{MCC} intervention for older adults with multiple chronic conditions: the DICO study. submitted). 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. Figure 1 presents the flow chart of the study.

Procedure

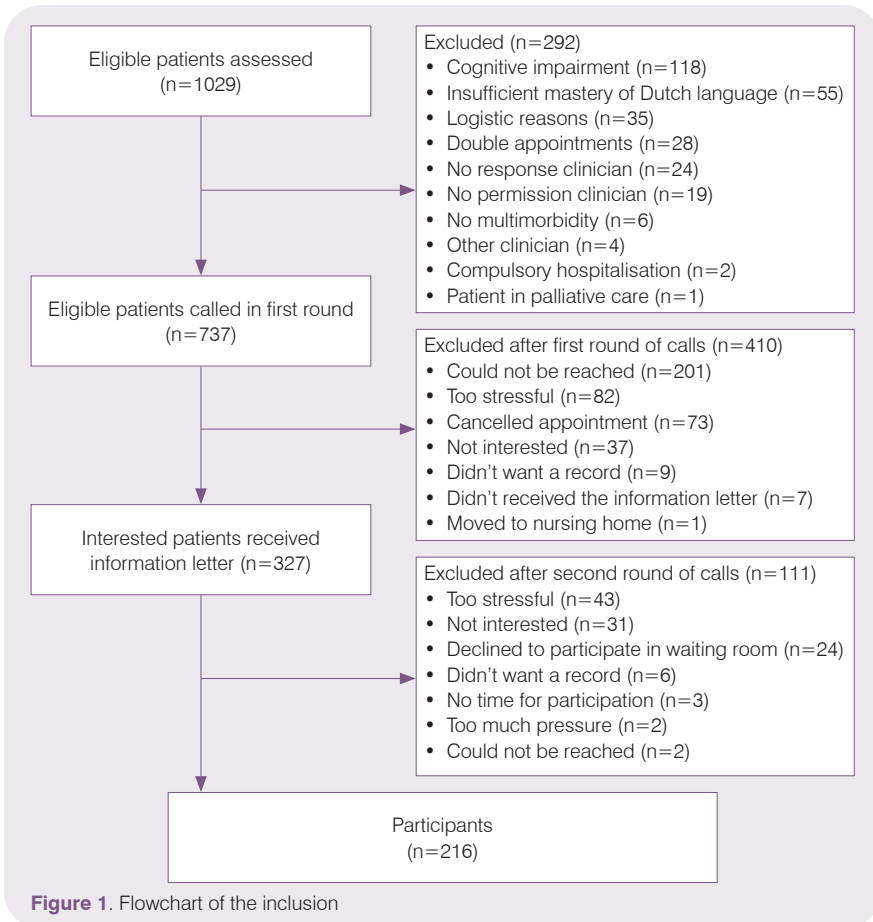
Eligible patients were contacted in advance by two research assistants. Interested patients received an information letter with an informed consent form. The consultations of the included patients were video recorded to enable rating by different observers. The observers were not present during the consultation. In addition, data were collected through pre- and post-consultation questionnaires. A research assistant was present in the waiting room to assist with the questionnaires if needed. 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^{44, 45}.

Measurements

Personal characteristics

The participants background characteristics included age, gender and education.

- *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).
- *Health literacy* was measured with the Short Assessment of Health Literacy in Dutch (SAHL-D22)^{46, 47}. 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)^{48, 49}. The STAI-6 consists of 6 items and has been proven to be reliable and valid for measuring anxiety⁵⁰⁻⁵². 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 levels⁵²⁻⁵⁵.
- *Frailty* was measured using the Groningen Frailty Indicator (GFI). The GFI is a validated self-reported screening instrument consisting of 15-items⁵⁶. The total score ranged from 0 to 15, with a score of four or higher considered the cut-off point for frailty⁵⁶. Higher scores on the GFI indicated higher frailty levels.

Mediating variable

The level of participation in the SDM process during the consultation was measured with the Observer OPTION^{MCC} 57. The Observer OPTION^{MCC} was developed to measure triadic decision making in older adults with MCCs. 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.

Outcome variables

- 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 are calculated as the proportion of participants who report a score of nine on each of the three CollaboRATE questions^{14, 58, 59}.
- *Decisional Conflict* was measured with the Decisional Conflict Scale (DCS), a self-administered questionnaire developed by O'Connor et al⁶⁰⁻⁶². 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 scale⁶⁰. 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)⁶⁰. 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^{60, 62}.

Statistical analysis

Linear mixed model analyses were used to analyze the relationships among personal characteristics, participation in the SDM process and SDM outcomes (the perceived level of SDM and decisional conflict). First, the relationship of each personal characteristic with participation in the SDM process was analyzed. Second, the relationships among personal characteristics and the SDM outcomes were analyzed. Third, both personal relationships were analyzed with multivariable linear mixed model analyses in which all personal characteristics were analyzed 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. All analyses were performed with mixed models to take into account the correlated observations within departments and Stata (version 14) was used for all analyses.

Results

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 Figure 1). We found no significant difference in age or gender between the participating patients and the nonresponding patients.

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%). Of the participating patients, 31 (15.2%) had a low education level. The mean health literacy of the patients was 11.8 (SD 6.9), indicating moderate health literacy levels. The mean frailty score of the patients was 4.3 (SD 2.5), indicating frailty, and the mean STAI-6 score was 11.1 (SD 4.2), indicating a moderate level of anxiety.

Table 1. Participant Characteristics

	N^a=216
Mean age in years (SD)	77.3 (7.9)
Female sex (n, %)	120 (56.3)
Level of education	
Low (n, %)	31 (15.2)
Middle (n, %)	118 (57.8)
High (n, %)	55 (27.0)
Health literacy (SAHL-D22) ^b (mean, SD)	11.8 (6.9)
Frailty (GFI) ^c mean, SD	4.3 (2.5)
Anxiety (STAI) ^d pre-consultation	11.1 (4.2)

^a n varies slightly due to missing data

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

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

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

Primary findings

Table 2 shows the relationship between each personal characteristic and observed participation in the SDM process. The multivariable analysis shows that health literacy (β .02, $P < .001$) was significantly related to observed participation in the SDM process (mean OPTION^{MCC}). Although the univariable analysis shows that age (β -.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 2. The relationship of personal characteristics and observed participation in SDM

Variable	univariable analysis			multivariable analysis ^a		
Education	N=201			N=183		
	β	95% CI	p-value	β	95% CI	p-value
OPTION 1	.06	(-.16;.28)	.59	-.08	(-.33;.17)	.53
OPTION 2	.06	(-.15;.28)	.56	-.07	(-.32;.18)	.60
OPTION 3	.10	(-.16;.36)	.46	.06	(-.25;.36)	.72
OPTION 4	.11	(-.11;.34)	.33	-.19	(-.44;.06)	.13
OPTION 5	.14	(-.09;.38)	.23	-.14	(-.40;.12)	.30
OPTION 6	.21	(-.01;.42)	.06	.08	(-.16;.31)	.54
OPTION 7	.10	(-.13;.33)	.38	-.04	(-.30;.23)	.78
Mean OPTION	.11	(-.05;.27)	.19	-.06	(-.24;.12)	.53
Age	N=205					
	β	95% CI	p-value	β	95% CI	p-value
OPTION 1	-.01	(-.02;.00)	.12	.00	(-.02;.01)	.59
OPTION 2	-.01	(-.02;.00)	.03*	-.01	(-.02;.00)	.16
OPTION 3	-.01	(-.02;.01)	.35	-.01	(-.02;.00)	.18
OPTION 4	-.01	(-.03;.00)	.02*	-.01	(-.02;.01)	.33
OPTION 5	-.01	(-.02;.01)	.34	.00	(-.01;.01)	.72
OPTION 6	-.01	(-.02;.00)	.13	.00	(-.02;.01)	.51
OPTION 7	-.01	(-.02;.00)	.08	-.01	(-.02;.01)	.28
Mean OPTION	-.01	(-.02;.00)	.03*	.00	(-.01;.00)	.26
Health literacy	N=190					
	β	95% CI	p-value	β	95% CI	p-value
OPTION 1	.02	(.01;.03)	.00**	.02	(.01;.04)	.01**
OPTION 2	.01	(.00;.03)	.04*	.02	(.00;.03)	.03*
OPTION 3	.01	(-.01;.02)	.30	.01	(-.01;.03)	.30
OPTION 4	.03	(.02;.04)	<.001***	.04	(.02;.05)	<.001***
OPTION 5	.03	(.02;.04)	<.001***	.04	(.02;.05)	<.001***
OPTION 6	.02	(.01;.04)	<.001***	.02	(.01;.04)	.00**
OPTION 7	.02	(.00;.03)	.03*	.02	(.00;.03)	.03*
Mean OPTION	.02	(.01;.03)	<.001***	.02	(.01;.03)	<.001***

Table 2. Continued

Frailty	N=192					
	β	95% CI	p-value	β	95% CI	p-value
OPTION 1	-.02	(-.06;.02)	.26	-.03	(-.07;.01)	.21
OPTION 2	-.01	(-.04;.03)	.73	.01	(-.04;.05)	.78
OPTION 3	-.02	(-.06;.03)	.42	.00	(-.05;.05)	.89
OPTION 4	-.02	(-.06;.02)	.25	-.02	(-.06;.02)	.36
OPTION 5	.01	(-.03;.05)	.62	.02	(-.03;.06)	.46
OPTION 6	-.01	(-.04;.03)	.74	.00	(-.04;.04)	.88
OPTION 7	-.02	(-.06;.02)	.29	-.02	(-.06;.02)	.36
Mean OPTION	-.01	(-.04;.02)	.42	-.01	-.04;.02	.65
Anxiety	N=188			N=183		
	β	95% CI	p-value	β	95% CI	p-value
OPTION 1	.01	(-.01;.04)	.35	.02	(-.01;.05)	.14
OPTION 2	-.01	(-.03;.02)	.68	-.01	(-.03;.02)	.66
OPTION 3	-.01	(-.04;.02)	.40	-.01	(-.05;.02)	.44
OPTION 4	.00	(-.02;.03)	.86	.01	(-.02;.04)	.48
OPTION 5	.01	(-.01;.04)	.32	.00	(-.03;.03)	.89
OPTION 6	.01	(-.01;.04)	.35	.01	(-.02;.04)	.50
OPTION 7	.01	(-.02;.03)	.57	.01	(-.02;.04)	.46
Mean OPTION	.01	(-.01;.02)	.58	.01	(-.01;.03)	.60

^a Multivariable analysis: multivariable linear mixed model analyses in which all personal characteristics were analyzed together

* < .05

** < .01

*** < .001

The influence of personal characteristics on the perceived level of SDM and decisional conflict are depicted in Table 3. The multivariable analysis shows that anxiety (β -.26, P = .06) and education (high education level versus middle and lower education level) (β -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 (β .01, P = .92), frailty (β -.25, P = .24) and age (β .01, P = .83) had no significant effect on the perceived level of SDM. Health literacy (β -.70, P = .01), anxiety (β 1.19 P < .001) and education (β 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 (β -.01, P = .99) and age (β .04, P = .83) had no significant effect on decisional conflict.

Table 3: The influence of personal characteristics on the perceived level of SDM and decisional conflict

Perceived level of SDM^a					N^b = 155		
	N ^{bd}	Univariable analysis			Multivariable analysis ^c		
		B	95% CI	p-value	B	95% CI	p-value
Education	164	-2.20	(-4.32;-.09)	.04*	-2.43	(-4.91; .042)	.05
Age	164	.01	(-.10;.12)	.85	.01	(-.10; .13)	.83
Health Literacy	159	-.05	(-.19;.08)	.46	.01	(-.17; .15)	.92
Frailty	161	-.38	(-.75;-.01)	.04*	-.25	(-.66; .17)	.24
Anxiety	159	-.32	(-.56;-.08)	.01**	-.26	(-.53; .01)	.06

Decisional Conflict^e					N^b = 137		
	N ^{bd}	Univariable analysis			Multivariate analysis		
		B	95% CI	p-value	B	95% CI	p-value
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
Health Literacy	140	-.47	(-.91;-.03)	.04*	-.70	(-1.19; -.20)	.01*
Frailty	141	.88	(-.29;2.04)	.14	-.01	(-1.23; 1.21)	.99
Anxiety	140	1.29	(.53;2.06)	<.001***	1.19	(.38; 2.01)	<.001**

^a SDM: CollaboRATE % 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 4 shows that the effect of health literacy on decisional conflict was mediated by participation in the SDM process. This finding means that the effect of health literacy on decisional conflict partly goes through participation in the SDM process. Table 5 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 4. The mediating influence of participation in the SDM process in the relationship between personal characteristics and decisional conflict

Decisional Conflict	N=137											
	VARIABLE						Anxiety					
	Education		Health Literacy		Anxiety		Education		Health Literacy		Anxiety	
	β	95% CI	p-value	β	95% CI	p-value	β	95% CI	p-value	β	95% CI	p-value
OPTION 1	12.10	(4.40; 19.80)	.00**	-.65	(-1.14; -.16)	.01*	1.24	(.51; 1.97)	.00**	1.24	(.51; 1.97)	.00**
OPTION 2	11.98	(4.39; 19.57)	.00**	-.60	(-1.07; -.13)	.01*	1.21	(.50; 1.92)	.00**	1.21	(.50; 1.92)	.00**
OPTION 3	12.38	(4.67; 2.09)	.00**	-.67	(-1.14; -.20)	.01*	1.22	(.50; 1.95)	.00**	1.22	(.50; 1.95)	.00**
OPTION 4	11.39	(3.74; 19.03)	.00**	-.48	(-.10; .029)	.06	1.25	(.54; 1.97)	.00**	1.25	(.54; 1.97)	.00**
OPTION 5	11.38	(3.78; 18.98)	.00**	-.48	(-.98; .02)	.06	1.31	(.59; 2.02)	.00**	1.31	(.59; 2.02)	.00**
OPTION 6	11.82	(4.18; 19.47)	.00**	-.57	(-1.06; -.07)	.03*	1.24	(.53; 1.96)	.00**	1.24	(.53; 1.96)	.00**
OPTION 7	12.22	(4.71; 19.72)	.00**	.54	(-1.02; -.07)	.02*	1.30	(.59; 2.00)	.00**	1.30	(.59; 2.00)	.00**
Mean OPTION	11.71	(4.15; 19.27)	.00**	-.47	(-.97; .03)	.07	1.28	(.57; 2.00)	.00**	1.28	(.57; 2.00)	.00**

* < .05

** < .01

*** < .001

Table 5. 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
OPTION 1	-2.15	(-4.34; .04)	.05	-.32	(-.56; -.08)	.01*
OPTION 2	-2.16	(-4.35; .04)	.05	-.33	(-.57; -.09)	.01*
OPTION 3	-2.45	(-4.62; -.27)	.03*	-.32	(-.55; -.08)	.01*
OPTION 4	-2.12	(-4.3; .07)	.06	-.33	(-.57; -.09)	.01*
OPTION 5	-2.17	(-4.37; .03)	.05	-.33	(-.57; -.09)	.01*
OPTION 6	-2.15	(-4.36; .05)	.06	-.33	(-.57; -.09)	.01*
OPTION 7	-2.42	(-4.6; .23)	.03*	-.35	(-.58; -.11)	.01*
Mean OPTION	-2.23	(-4.44; -.02)	.05	-.33	(-.57; -.09)	.01*

* < .05

** < .01

*** < .001

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 mediated this effect for health literacy on decisional conflict.

Previous studies have focused on the relation between low health literacy and SDM outcomes regarding the use of decision aids, but comparing the results of these studies is difficult because our research focused on actual participation in the SDM process during a consultation. The reviews by Mccafferty et al (2013) and Stacey (2017) et al provide evidence that lower literacy is related to higher decisional conflict in the context of using patient decision aids^{63, 64}. Additionally, these reviews indicate that adults with low literacy levels have a lower desire to participate in SDM^{63, 64}. 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 tailored⁶⁵. However, these interventions mainly target patient decision aids, videos and patient training (pre-consultation). Future research should focus on how to improve participation in the SDM process during a consultation to enhance the positive effects on the perceived level of SDM and decisional conflict for older adults with low health literacy. Furthermore, 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 practice⁶⁶. 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^{66, 67}.

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 motivation⁶. 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 SDM⁷. On the other hand the complexity of the situation of frail adults, such as the aspect of MCCs, may hinder their participation in SDM^{68, 69}. 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 relationship⁷⁰, but other studies report that a higher level of education is associated with higher levels of perceived SDM⁷¹ and higher 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, the informal caregiver is present during the consultation and may participate in SDM on behalf of the patient. However, we did not further explore these relationships in this 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, 24, 72, 73}. 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”⁷⁴. This process requires skills from health professionals to anticipate the barriers very old adults experience in SDM.

Strengths and limitations

The results of this study must be interpreted in the of some methodological considerations. 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. Due to the frailty of the patient population and the size of the sample, we were limited in the number of characteristics that could be measured and 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 emotional wellbeing or gender, may also be associated with SDM outcomes and might be mediated by participation in SDM. 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.

Conclusion

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. Therefore, we recommend performing a health literacy assessment before SDM and that health professionals adapt their communication so that older adults with low health literacy are more empowered to participate in SDM. Further research is recommended for SDM with anxious older people so that they experience less decisional conflict.

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