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Experiences of patients with multimorbidity with primary care and the association with patient activation: a cross-sectional study in Germany

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Experiences of patients with multimorbidity with primary care and the association with patient activation: a cross-sectional study in Germany

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Abstract

Objectives The present study aimed to explore whether patients’ experiences with primary care were associated with patient activation among an elderly multimorbid population in Germany.

Design Cross-sectional study.

Setting Primary care practices in two German settings.

Participants 346 patients with three or more chronic conditions aged 65 years and over from 36 primary care practices.

Outcome measures Patient activation was measured with the Patient Activation Measure. To assess patient experiences with primary care, a set of questions concerning aspects of primary care were included. Multilevel regression analyses were performed to examine which aspects of care were associated with patient activation.

Results Mean PAM-score was 76.1. Across all patients, 3.8 % achieved PAM level 1, 7.5 % level 2, 27.2 % level 3 and 60.7 % level 4. In the regression analysis, the aspects ‘being involved in decision as much as desired’ (B=-8.56, p=0.012) and ‘receiving a self-management plan’ (B=6.51, p=0.051) were associated with higher patient activation scores. Patients with an up-to-date medication plan had lower patient activation scores (B=-12.01, p=0.041).

Conclusion Specific aspects of primary care were found to be associated with patient activation. To enhance patient activation, primary care physicians may increase involvement of patients in decisions. Future research should examine the causality of these associations.

Trial registration number

German clinical trials registry (DRKS00015718).

Key words Multimorbidity, Patient activation, Patient reported outcomes, Primary Care, Germany

Article summary

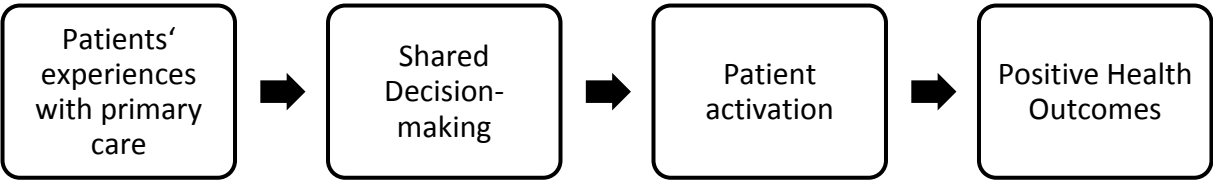
Strengths and limitations of this study

- Patients with various combinations of chronic diseases were surveyed in standardized interviews.
- Several factors concerning patient experiences with primary care were included in the multivariate analysis.
- Due to the cross-sectional design, we are not able making casual inferences about the relationship between patients' experiences of primary care, shared decision-making and patient activation.

Introduction:

About 62 % of patients aged 65 years or higher in Germany have three or more chronic conditions, which is defined as multimorbidity [1]. Multimorbidity is associated with higher healthcare utilisation and costs, lower quality of life and higher mortality [2, 3]. This has consequences not only for the patient but for the daily work of primary care physicians, whom are the main contact point of older multimorbid patients [4]. It is widely recognised that engaging patients in their own care is critical for successful health care systems as well as a crucial part in patient-centred care [5]. As described in the chronic care model by Wagner et al., it is assumed that *"interactions between practice team and patients that consistently provide the assessments, support for self-management, optimization of therapy, and follow-up are associated with good outcomes and leads to high-quality chronic illness care"* [6]. Patient activation highlights patients' willingness and ability to manage their health and care independently [5]. Shared decision-making, a key element in patient-centred care, gives patients the opportunity to participate and engage in their own health. Studies indicated that shared decision-making results in patient activation and self-management which in turn can result in better health outcomes [7, 8]. Therefore, active participation and self-management of patients is a crucial part in primary care, especially in patients with multimorbidity [6, 9]. Figure 1 shows the assumed pathways of shared decision-making and patient activation in this study.

Figure 1: Conceptual model: interaction between shared decision making and patient activation



The patient activation measure (PAM) is a 13 item questionnaire developed by Hibbard et al. in 2005 that focuses on “knowledge, skills and confidence that equip patients to become actively engaged in their own health” [10, 11, 12]. The measure has been widely used to measure the level of empowerment and self-management of chronically ill patients. PAM is based on the constructs self-efficacy, behaviour of change and knowledge of control. Its goal is to identify the level of activation of individuals, thus to support them in their healthcare and health-related behaviour according to their level. Tailoring care according to the level of activation may have positive effects on different health outcomes [10]. The developers have shown that higher levels of PAM are related to lower probability of emergency department (ED) visits, being obese or smoking, and a higher probability of seeking cancer screening and other recommended clinical procedures [10]. Other studies concluded that patients with higher levels of PAM are more likely to adhere to medical regimens, manage their chronic conditions, and less likely to be hospitalized [13–15]. Change in patient activation is related to positive changes in a variety of self-management behaviours, like doing physical exercises, managing stress or reading about side effects when taking new medication [16]. Furthermore, higher patient activation scores are associated with lower health care costs [17].

There are many studies reporting the effects of patient activation on clinical outcomes and health-related behaviour. Therefore, it would be helpful to identify which aspects that can be directly addressed by primary care physicians are linked to higher patient activation. Studies have shown that satisfaction with healthcare and primary care physicians contributed to higher patient activation scores [18–20]. Hibbard and colleagues found that patients whose physicians helped to monitor their health and set goals had higher patient activation scores [11]. Additionally, patients who trust their primary care physician had also higher scores [10, 21, 22]. A study about the patient-physician relationship and patient activation found that perceived higher quality of interpersonal exchanges with their physicians, being treated fair and respectful and more frequent communication with physicians outside consultation hours

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3 were associated with higher levels of PAM among chronically ill patients. Treatment goal
4 setting in this study was not associated with PAM [23]. Another study pointed out that primary
5 care providers who were convinced of patients' role of self-management correlated positively
6 with higher PAM scores in their patients [24]. Furthermore, patient activation and the concept
7 of shared-decision making, in which patients and physicians exchange information about
8 patient preferences and treatment options in a collaborative process [25], are known to be
9 associated [7].

10
11 Although patient activation and its associations has been studied extensively [10], the
12 evidence regarding patient experiences with primary care and its association to patient
13 activation is mainly from North America and largely over a decade old. Furthermore, only few
14 studies focused on older patients with multimorbidity [18–20].

15
16 Germany's healthcare system is characterized by a number of unique features such as
17 universal coverage through health insurance, prominent role of physicians (rather than nurses
18 and others), frequent (short) contacts to the primary care physician, and emphasis on internal
19 medicine in the vocational training of primary care physicians [26, 27]. Therefore, it is
20 uncertain whether the findings of previous studies on patient activation can be generalized to
21 the primary care setting among multimorbid patients in Germany. Thus, the aim of this study
22 was to identify which patients' experiences regarding primary care are associated with patient
23 activation among a population of older patients with multimorbidity in Germany.

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Methods

Study design and population

This study had a cross-sectional design. Data was collected as part of the project *Development and Validation of Quality Indicators for Multimorbidity* (MULTIqual), which aims at developing a set of indicators for primary care providers for patients with multimorbidity [28, 29].

Eligible participants were patients aged 65 years or older with three or more chronic conditions. The conditions were: anaemia, diabetes mellitus, obesity, depression, anxiety disorder, Parkinson's disease, mono- and polyneuropathy, vertigo, chronic ischaemic heart disease, angina pectoris, heart failure, peripheral artery disease (PAD), atherosclerosis, asthma, chronic obstructive pulmonary disease (COPD), chronic bronchitis, arthrosis, osteoporosis, urinary incontinence, malignant tumours. The list is derived from a previous

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study in Germany regarding patterns of multimorbidity [30]. Patients with severe cognitive impairment, hearing impairment, terminal illness and substitute patients were excluded.

Patients were recruited in primary care practices from two regions of Germany (Hamburg and Heidelberg and environs). A total of 889 primary care physicians in general practices were randomly selected and invited to take part in the study, of whom 36 (4%) agreed to participate. Primary care practices were asked to recruit patients over 65 years that had visited the practice within the last three months. All in all, 1243 patients were invited to take part in the study. Eligible patients received a letter signed by their primary care physician including the study materials (the information leaflet including contact details of the research team, a contact form and the declaration of consent).

The study was approved by the Ethics Committee of the Hamburg Medical School (PV5846), the Ethics Committee of the Medical Faculty of the Heidelberg University (S-665/2018) as well as the Baden-Wuerttemberg regional medical board (B-F-2018-096). The study has been registered at the German Clinical Trial Register prior to the start of the study (registration no. DRKS00015718).

The STROBE guideline was used for reporting this study.

Data collection

Data were collected via standardized, face-to-face interviews. Patients who were interested to participate in the study were requested to return the completed contact form and declaration of consent to be contacted by telephone by the research team. After a telephone appointment with potential participants, a member of the research team visited the participant at home or at the primary care practice. Patients were again informed about the study and gave written consent to participate directly before the interview. Standardized interviews based on a paper-based questionnaire were conducted between July 2019 and February 2020.

Measures

The questionnaire was read out to the patient and the response options for the validated measures were laid out on a card in front of the participant. Socio-demographic data including age, gender, marital status, education level, country of birth and native language were collected.

The outcome variable patient activation was measured with the 13-item validated version in German (PAM-13D). PAM-13D includes statements regarding patients' beliefs about health care, self-assessed knowledge, and confidence in their ability to manage their conditions [10, 11]. Each statement is rated by the individual participant on the response scale of 1 to 4 (German version) where 1 represents "*disagree strongly*" and 4 represents "*agree strongly*". To calculate PAM scores (ranging from 0 to 100), we used the standardised spreadsheet provided by the developers (Insignia Health), which transforms the German response options into standardized metrics. Higher scores indicate that the patient is more activated [31]. Patients can be classified based on their overall score into one out of four levels. Patient in level 1 may not understand their role in decision-making about their health and tend to be passive. Level 2 includes patients who may still lacking knowledge and confidence to manage their health. In level 3, patients are more active but may still struggle to manage all aspects of health behaviour. Patients in level 4 can manage their health but may not be able to stay the course under stress [31].

To assess patients' experiences of primary care, we asked them a set of different questions relating to aspects of high-quality care. The aspects were derived from a systematic review of guidelines, focus groups with patients with multimorbidity and their relatives and selected and consented by an expert panel. They are suggested as indicators for the quality of care for patients with multimorbidity [28, 29]. Aspects of care covered were a) preferences in treatment b) treatment goals, c) involvement in treatment, d) patient training programme e) support group f) self-management plan, g) medication plan, h) review on medication, i) information on medication and j) discussion about their treatment burden. The questions had mostly three response options (*yes, no and I do not know*). Response options for the question concerning involvement in care (c) were '*always*' or '*usually*'/ '*rarely*'/ '*never*'. All answers/items were dichotomized.

Statistical analysis

Descriptive statistics were calculated for all variables included in the analysis to examine means, standard deviation, distribution for continuous variables, and frequencies for categorical data. A regression analysis was performed in order to assess potential effect of patients' experiences of primary care on patient activation. PAM score was treated as the dependent variable whereas the reported patients' experiences of primary care were treated

as independent variables. Due to the hierarchical structure of the data, the regression analysis was based on a linear multilevel model with a random intercept for primary care practices in which patients were nested. In the analysis, we controlled for patients' age and gender. The linear model was chosen due to the approximately normal distribution of the residuals in the Q-Q-Plot. In all analyses, $p < 0.05$ was considered significant. Multicollinearity analysis showed variance inflation factors of less than 1.4, therefore multicollinearity did not pose a substantial problem [32]. We used IBM SPSS version 25.0 for statistical analysis.

Results

Table 1: Characteristics of the study population

Sample characteristic	Sample description (n = 346)
Age, mean (SD)	77.4 (7.0)
Gender, n (%)	
- female	191 (55.2)
- male	155 (44.8)
Marital status, n (%)	
- married	189 (54.6)
- unmarried/ single	23 (6.6)
- divorced	34 (9.8)
- widowed	100 (28.9)
Living alone	
- Yes	124 (35.8)
- No	222 (64.2)
Country of birth, n (%)	
- Germany	320 (92.5)
- other country	26 (7.5)
Native language, n (%)	
- German	340 (99.1)
- other	3 (0.9)
CASMIN (educational classification) n (%)	
- level 1 (no/ low education level with/ without vocational training)	193 (56.1)
- level 2 (middle/ high education level with/ without vocational training)	96 (27.9)
- level 3 (high education level)	55 (16.0)
Employment situation, n (%)	
- Working	8 (2.3)
- Retired/not economically active	338 (97.7)
Nursing care dependency, n (%)	
- Yes	78 (22.5)
- No	268 (77.5)

Health insurance, n (%)	
- insured under a statutory insurance plan	324 (93.6)
- privately insured	22 (6.3)
(Self-reported) Chronic conditions, mean (SD)	9.9 (4.4)
Patient Activation Measure (PAM Score).	
mean (SD)	76.1 (16.4)
PAM Level n (%)	
- level 1 (≤ 47.0) (least activated)	13 (3.8)
- level 2 (≥ 47.1 and ≤ 55.1)	26 (7.5)
- level 3 (≥ 55.2 and ≤ 72.4)	94 (27.2)
- level 4 (≥ 72.5) (most activated)	210 (60.7)
- missing	3 (0.9)

Out of 1243 invited patients a total of 346 took part in the study (participation rate 27.8 %). First, we present the characteristics of the study sample (Table 1). Patients were, on average 77.4 (± 7) years old and predominantly born in Germany. Their educational qualification was relatively low with 55.8 % of the sample being in Level 1 of the Comparative Analysis of Social Mobility in Industrial Nations (CASMIN), including all respondents with elementary education with or without basic vocational qualification. Mostly all participants were retired or not economically active (97.7%) and reported on average of 9.9 (± 4.4) chronic conditions. Across all respondents, the mean PAM score was 76.1 with a median of 75, ranging from 22.6 to 100. Nearly two thirds of all participants had patient activation scores of 72.5 and higher (level 4). Exceedingly few participants reported lower activation scores (level 1 and 2). There was no significant difference in PAM scores between the two study sites.

Table 2: Influences from patients' experiences of primary care on PAM scores (multilevel model with a random intercept with patients nested within primary care practices)

	B (SE)	95 % CI	p
Age	-0.24 (0.21)	-0.66 to -0.17	0.224
Gender	2.65 (2.87)	-3.02 to 8.33	0.356
Did your primary physician ask you about your preferences in your treatment?	-0.33 (3.13)	-6.53 to 5.85	0.914
Have you agreed on treatment goals with your primary physician?	-0.29 (3.04)	-6.32 to 5.73	0.922
Do you feel as involved in decisions about your	-8.56 (3.36)	-15.21 to -1.91	0.012*

treatment as you would like to be?*			
Have you been offered participation in a patient training programme after your diagnosis?	-1.15 (3.52)	-8.12 to 5.82	0.744
Have you been offered the opportunity to participate in a support group after your diagnosis?	0.52 (4.62)	-8.63 to 9.68	0.910
Have you received a written (self-management) plan about what you can do to improve your health?	6.51 (3.30)	-0.02 to 13.06	0.051
Do you have a medication plan?*	-12.01 (5.83)	-23.55 to -0.48	0.041*
In your opinion is this medication plan up-to-date?	6.75 (5.16)	-3.46 to 16.97	0.194
Has your primary physician reviewed your medication with you in the last 12 months?	-1.86 (3.33)	-8.47 to 4.73	0.576
Has your primary physician explained to you how and when you should take the medication?	7.65 (4.37)	-0.99 to 16.31	0.083
Has your primary physician discussed with you how you cope with the burden of the chronic disease?	2.26 (3.22)	-4.11 to 8.64	0.484

Table 2 presents the results of the multilevel regression analysis. The aspects ‘involvement in treatment’ and ‘receiving a medication plan’ showed significant effects in the multilevel model. The aspect of ‘receiving a self-management plan’ was close to the significant threshold and thereby also considered as relevant. Controlling for age and gender, we found that patients who stated they were not always as involved in decisions about their treatment as far as they would want to, had lower scores on the measure of patient activation (B= -8.56, p=0.012). These results indicate that, on average, a change of the response option from

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3 'always' to 'usually/infrequent/never' was associated with an 8.56 decrease in a patient's
4 reported level of activation. Furthermore, we found that patients who reported that they
5 received a self-management plan from their primary care physician were more likely to have
6 higher patient activation scores ($B = 6.51$, $p = 0.051$). This indicates that if patients changed their
7 response option from 'yes' to 'no', on average, the PAM score increased by 6.51 units. In
8 contrast, if patients stated that they received an up-to-date medication plan from their
9 primary care physician the patient activation scores decreased by 12.01 units ($p = 0.041$) (Table
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18 Discussion

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20 The objective of this study was to analyse the association of patients' experiences with
21 primary care and patient activation among an older multimorbid population. Our results
22 indicate that there are aspects of primary care, which are associated with patient activation.
23 Receiving written information on self-management tasks as well as involvement in care was
24 found to be associated with higher patient activation scores. Receiving a medication plan was
25 found to be associated with lower patient activation scores.
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32 Our findings on the distribution of PAM scores show that patients in this study were on
33 average highly activated, which is inconsistent with the majority of existing studies on patient
34 activation. Studies with a comparable sample of patients in age and diseases show mean PAM
35 scores around about 60 [11, 18, 33]. However, there are studies with highly activated patients,
36 for example Greene et al. [12] found 61.1 % in the highest activation level in a convenience
37 sample of adults aged 65 and older. Furthermore, in an international comparison of
38 psychometric properties and scores of PAM, German patients had the highest scores with a
39 mean of 67.2 [34]. Even though such high scores are unexpected, one explanation may be that
40 the standardised interviews took place in person, hence social desirability may be an impact.
41 Participating population (both physicians and patients) were willing to participate in research,
42 hence highly motivated. Thus, it seems quite likely that those were activated individuals with
43 an interest in conversations about health and healthcare. Using the PAM as an outcome
44 measure carries the risk that high scores will be seen as 'better' and a linear increase in scores
45 is expected [35]. However, previous research has shown that patients starting at a low
46 activation score are more likely to increase activation [36]. In addition, patients can also shift
47 between PAM levels if their condition or treatment changes. Moreover, it could also be a
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positive outcome for some patients to maintain their activation level rather than to increase it. Especially for older multimorbid patients with already high activation scores, as in our study, this could be the case.

Our findings are, for the most part, in line with the assumed conceptual model between shared decision making and patient activation and their link to positive health outcomes. The findings of patient’s experiences with primary care could explain the connections.

Patients that were satisfied with the extent they were being involved in decisions also received higher results for patient activation. This suggests that fostering shared decision making and involvement from a passive role could be associated with changes in behaviours and attitudes among multimorbid patients. Our findings are supported by a study by Wensing et al. that examined patient enablement, a relating concept to patient activation and its association to involvement. They found that older patients in Europe how positively evaluated their involvement in primary care were more likely to be enabled, if the patient had a high preference for involvement the impact of evaluation on enablement was even higher. The authors concluded that improving patient evaluation of involvement in care may impact and enhance their enablement [37]. A clinical review on the management of multimorbid patients in primary care outlined that in the context of multimorbidity and shared decision making it is crucial to determine what matters most to the patient [4]. Our results indicate that some patients would like to be more involved in treatment, which may influence their activation level. It is therefore surprising that the aspects of the preferences in the treatment as well as treatment goal setting was not significant in the multilevel analysis. Related to treatment goal agreements, studies showed various results. Alexander et al. [23] declared that goal setting places major responsibility on patients, as they have to understand the specifics of the conditions and alternative therapy approaches. Our study results show an association between patient involvement and patient activation but cannot show causality. Hence, it is possible that patient activation is cause or consequence of patient involvement. The direction of the relationship remains unclear.

Another unexpected result was the finding that PAM scores were lower if patients received an up-to-date medication plan. Previous studies have shown that patients with higher activation scores are more likely to adhere to medication plans [13–15]. An explanation for our results could be that patients without a medication plan might have fewer medication and

therefore fewer chronic conditions. Thus, they are healthier. A written medication plan does not necessarily support patients' autonomy in decision-making. An alternative explanation for our findings is that medication plans could support a more passive patient role.

In contrast, our data indicate a positive association between receiving a self-management plan and higher patient activation. Even though the aspect is only close to the significant threshold ($p=0.051$), we consider the aspect relevant. It suggests that having a plan with instructions on self-management may enhance activation. The interpretation is supported by the finding that patient activation is linked to positive changes in a variety of self-management behaviour, like doing exercises, managing stress or reading about the side effects of new medication [16]. Another unexpected finding is that the offer to participate in patient training programmes or support groups showed no significant effect. Again, we are not able to draw conclusions concerning the direction of associations between the aspects of receiving a medication plan or a self-management plan and patient activation.

The aspect of the information on new medication is also close to the significant threshold ($p=0.083$) and thereby may also be a relevant aspect for primary care physicians to consider for enhancing patient activation. Explaining and discussing new prescriptions is an important step in involving patients actively in their care. These results are in line with a study by Hibbard et al. [16] that reading about side effects when taking new medication were associated with higher patient activation scores.

Previous research has demonstrated a 4-6-point difference on the PAM scale as practically meaningful [16, 38, 39]. This undermines the practical relevance of our results on patients' experiences of primary care and its association to patient activation. Given the wide usage and the potential patient activation has been shown on health-related outcomes in other countries as well as the sparse research on this subject in Germany, our findings could help to identify older patients with multimorbidity, who indicate care problems, which may influence patient activation.

Practice implications

Primary care physicians should be aware that improving patients' experiences of their involvement in care and distribution of self-management plans may help to enhance their activation. This is particularly important in chronic care, where self-management is key in

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chronic disease management [9]. Efforts to improve involvement and thereby increase activation of patients with multimorbidity should focus on the individual patient as well as on the aspects proceeding in primary care practices and the relationship of patients and their primary care physicians. Primary care patients should direct their attention at asking their multimorbid patients how far they want to be involved in their care, if they want to set up self-management tasks in a written plan as well as to explain and discuss the prescription of medication. Further analysis of longitudinal studies will be necessary to gain insight into the causal relationship between patient activation, shared decision-making and patients' experiences of primary care.

Strengths and limitations

Our results are limited by the cross-sectional design, which precludes making casual inferences about the relationship between patients' experiences of primary care, shared decision-making and patient activation. The results should be seen under the fact that our study population consisted of a heterogenous group of people with different diseases and at different stages of their diseases. Moreover, several factors concerning patients' experiences with primary care were included. Since the purpose was to investigate the experiences of primary care and its association with patient activation, we did not analyse the direct impact of different comorbidities on patient activation.

Conclusion

The results point out the importance of including patients in treatment and a plan that helps coordinating self-management as a crucial part in patient activation and primary care, thus changing patient behaviours and attitudes toward their care. Understanding the factors regarding patients' experiences of primary care practices and the association with patient activation may help primary physicians to enhance involvement, shared decision-making and thereby activation of their patients.

Data availability statement

No data are available. The data generated and analysed during the current study are not publicly available due to the study's assurances to participants that raw data would not be shared publicly.

Ethics declaration

The study was approved by the Ethics Committee of the Hamburg Medical School (PV5846), the Ethics Committee of the Medical Faculty of the Heidelberg University (S-665/2018) as well as the Baden-Wuerttemberg regional medical board (B-F-2018-096).

Author contributions

MS, JSz contributed to the conception and design of the study. AB, KG and JS collected the data. AB performed data analysis and drafted the manuscript. All authors critically revised the draft and approved submission of the final version.

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Conflicts of interest

None.

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Reporting checklist for cross sectional study.

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			Page
Reporting Item			Number
Title and abstract			
Title	#1a	Indicate the study's design with a commonly used term in the title or the abstract	1

1	Abstract	#1b	Provide in the abstract an informative and balanced summary	2
2			of what was done and what was found	
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6	Introduction			
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10	Background /	#2	Explain the scientific background and rationale for the	3-5
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15	Objectives	#3	State specific objectives, including any prespecified	5
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23	Study design	#4	Present key elements of study design early in the paper	5-6
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26	Setting	#5	Describe the setting, locations, and relevant dates, including	5-6
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34	Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of	5-6
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47	Data sources /	#8	For each variable of interest give sources of data and details	5-7
48	measurement		of methods of assessment (measurement). Describe	
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Bias	#9	Describe any efforts to address potential sources of bias	7-8
Study size	#10	Explain how the study size was arrived at	6
Quantitative variables	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	7-8
Statistical methods	#12a	Describe all statistical methods, including those used to control for confounding	7-8
Statistical methods	#12b	Describe any methods used to examine subgroups and interactions	7-8
Statistical methods	#12c	Explain how missing data were addressed	
Statistical methods	#12d	If applicable, describe analytical methods taking account of sampling strategy	
Statistical methods	#12e	Describe any sensitivity analyses	
Results			
Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	8-9
Participants	#13b	Give reasons for non-participation at each stage	

1	Participants	#13c	Consider use of a flow diagram	
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4	Descriptive data	#14a	Give characteristics of study participants (eg demographic,	8-9
5			clinical, social) and information on exposures and potential	
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11	Descriptive data	#14b	Indicate number of participants with missing data for each	
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14	Outcome data	#15	Report numbers of outcome events or summary measures.	
15			Give information separately for exposed and unexposed	
16			groups if applicable.	
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20	Main results	#16a	Give unadjusted estimates and, if applicable, confounder-	9-11
21			adjusted estimates and their precision (eg, 95% confidence	
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27	Main results	#16b	Report category boundaries when continuous variables were	
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32	Main results	#16c	If relevant, consider translating estimates of relative risk into	
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37	Other analyses	#17	Report other analyses done—e.g., analyses of subgroups	
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53	Discussion			
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Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	14
Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	11-14
Generalisability	#21	Discuss the generalisability (external validity) of the study results	11-14
Other Information			
Funding	#22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	15

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BMJ Open

Experiences of patients with multimorbidity with primary care and the association with patient activation: a cross-sectional study in Germany

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Experiences of patients with multimorbidity with primary care and the association with patient activation: a cross-sectional study in Germany

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Abstract

Objectives The present study aimed to explore the association between patient activation and patients’ experience of care among an elderly multimorbid population in Germany.

Design Cross-sectional study.

Setting Primary care practices in two German settings.

Participants 346 patients with three or more chronic conditions aged 65 years and over from 36 primary care practices.

Outcome measures Patient activation was measured with the Patient Activation Measure. To assess patient experiences with primary care, a set of questions concerning domains of primary care were included. Multilevel regression analyses were performed to examine which domains of care were associated with patient activation.

Results Out of 1243 invited patients a total of 346 took part in the study (participation rate 27.8 %). Mean PAM-score was 76.1. Across all patients, 3.8 % achieved PAM level 1, 7.5 % level 2, 27.2 % level 3 and 60.7 % level 4. PAM scores suggest a highly activated patient group. In the regression analysis, three out ten domains of patients’ experiences showed an association with patient activation. The domains ‘being involved in decision as much as desired’ (B=-8.56, p=0.012) and ‘receiving a self-management plan’ (B=6.51, p=0.051) were associated with higher patient activation scores. Patients with an up-to-date medication plan had lower patient activation scores (B=-12.01, p=0.041).

Conclusion Specific domains of primary care were found to be associated with patient activation. To enhance patient activation, primary care physicians may increase involvement of patients in decisions. Future research should examine the causality of these associations.

Trial registration number

German clinical trials registry (DRKS00015718).

Key words Multimorbidity, Patient activation, Patient reported outcomes, Primary Care, Germany

Article summary

Strengths and limitations of this study

- Patients with various combinations of chronic diseases were surveyed in standardized interviews.
- Several factors concerning patient experiences with primary care were included in the multivariate analysis.
- Due to the cross-sectional design, we are not able making casual inferences about the relationship between patients' experiences of primary care, shared decision-making and patient activation.

Introduction:

About 62 % of patients aged 65 years or higher in Germany have three or more chronic conditions, which is defined as multimorbidity [1]. Multimorbidity is associated with higher healthcare utilisation and costs, lower quality of life and higher mortality [2, 3]. This has consequences not only for the patient but for the daily work of primary care physicians, whom are the main contact point of older multimorbid patients [4]. It is widely recognised that engaging patients in their own care is critical for successful health care systems as well as a crucial part in patient-centred care [5]. As described in the chronic care model by Wagner et al., it is assumed that *"interactions between practice team and patients that consistently provide the assessments, support for self-management, optimization of therapy, and follow-up are associated with good outcomes and leads to high-quality chronic illness care"* [6]. Patient activation highlights patients' willingness and ability to manage their health and care independently [5]. Shared decision-making, a key element in patient-centred care, gives patients the opportunity to participate and engage in their own health. Studies indicated that shared decision-making results in patient activation and self-management which in turn can result in better health outcomes [7, 8]. Therefore, active participation and self-management of patients is a crucial part in primary care, especially in patients with multimorbidity [6, 9]. Figure 1 shows the assumed process association of shared decision-making and patient activation in this study. We assume that patient activation is an intrinsic characteristic which can be fostered by support such as shared decision making or patient centeredness. This is

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supported by the process model of Castro et al. [10] for the concepts of patient participation, patient-centeredness and patient empowerment, whereby patient activation is an attribute of patient empowerment [10]. The model declares that by “focusing on patient participation as a strategy, a patient centered approach is facilitated which leads to patient empowerment.”

The patient activation measure (PAM) is a 13 item questionnaire developed by Hibbard et al. in 2005 that focuses on *“knowledge, skills and confidence that equip patients to become actively engaged in their own health”* [11], [12, 13]. The measure has been widely used to measure the level of empowerment and self-management of chronically ill patients. PAM is based on the constructs self-efficacy, behaviour of change and knowledge of control. Its goal is to identify the level of activation of individuals, thus, to support them in their healthcare and health-related behaviour according to their level. Tailoring care according to the level of activation may have positive effects on different health outcomes [11]. The developers have shown that higher levels of PAM are related to lower probability of emergency department (ED) visits, being obese or smoking, and a higher probability of seeking cancer screening and other recommended clinical procedures [11]. Other studies concluded that patients with higher levels of PAM are more likely to adhere to medical regimens, manage their chronic conditions, and less likely to be hospitalized [14–16]. Change in patient activation is related to positive changes in a variety of self-management behaviours, like doing physical exercises, managing stress or reading about side effects when taking new medication [17]. Furthermore, higher patient activation scores are associated with lower health care costs [18]. Some studies looking at different interventions like online programs or walking interventions over a period of time showed that patient activation is changeable [19–22].

Thus, there are many studies reporting the association of patient activation with clinical outcomes and health-related behaviour. Therefore, it would be helpful to identify which aspects that can be directly addressed by primary care physicians are linked to higher patient activation. Studies have shown that satisfaction with healthcare and primary care physicians contributed to higher patient activation scores [23–25]. Hibbard and colleagues found that patients whose physicians helped to monitor their health and set goals had higher patient activation scores [12]. Additionally, patients who trust their primary care physician had also higher scores [11, 26, 27]. A study examining the association of patient-physician relationship

with patient activation among chronically ill patients found four relevant aspects [28]. Patients that report higher quality of interpersonal exchanges with their physicians, being treated fair and respectful and had more frequent communication with physicians outside the consultation hours were associated with higher levels of PAM. Treatment goal setting in this study was not associated with PAM [28]. Another study pointed out that primary care providers who were convinced of patients' role of self-management correlated positively with higher PAM scores in their patients [29]. The primary care providers' beliefs of the importance on patients' role were moderately positively correlated with a change in activation scores of patients [29]. Furthermore, patient activation and the concept of shared-decision making, in which patients and physicians exchange information about patient preferences and treatment options in a collaborative process [30], are known to be associated [7]. Especially in the area of patient activation and patient experiences of care longitudinal studies are rare [5], making it impossible to draw conclusions on the direction of causality. However, one study examined the relationship between changes in activation over three years and patient-assessed quality of chronic illness care among patients with type 2 diabetes. They showed that patient activation and patient-assessed quality of chronic illness care change in the same direction. The authors recommend to compare quality assessments within patient activation levels [31]. Moreover, a study from the authors of the PAM on approaches used by primary care providers whose patients had an increased activation level revealed five key strategies: They supported patient behaviour changes by emphasising patients' self-responsibility but also showing that they care for their concerns and working in partnership with their patients. Also identifying small steps and scheduling frequent follow-up visits to celebrate successes or solve problems were reported. Providers whose patients had lesser change in activation were far less likely to describe using these approaches [32].

Although patient activation and its associations has been studied extensively [11], the evidence regarding patient experiences with primary care and its association to patient activation is mainly from North America and largely over a decade old. Furthermore, only few studies focused on older patients with multimorbidity [23–25].

Germany's healthcare system is characterized by a number of unique features such as universal coverage through health insurance, prominent role of physicians (rather than nurses and others), frequent (short) contacts to the primary care physician, and emphasis on internal

medicine in the vocational training of primary care physicians [33, 34]. Therefore, it is uncertain whether the findings of previous studies on patient activation can be generalized to the primary care setting among multimorbid patients in Germany. Thus, the aim of this study was to identify which patients' experiences regarding primary care are associated with patient activation among a population of older patients with multimorbidity in Germany.

Methods

Study design and population

This study had a cross-sectional design. Data was collected as part of the project *Development and Validation of Quality Indicators for Multimorbidity* (MULTIqual), which aims at developing a set of indicators for primary care providers for patients with multimorbidity [35, 36].

Eligible participants were patients aged 65 years or older with three or more chronic conditions. The conditions were: anaemia, diabetes mellitus, obesity, depression, anxiety disorder, Parkinson's disease, mono- and polyneuropathy, vertigo, chronic ischaemic heart disease, angina pectoris, heart failure, peripheral artery disease (PAD), atherosclerosis, asthma, chronic obstructive pulmonary disease (COPD), chronic bronchitis, arthrosis, osteoporosis, urinary incontinence, malignant tumours. The list is derived from a previous study in Germany regarding patterns of multimorbidity [37]. These conditions were chosen as they impose symptom burden on patients and are accompanied with taking a considerable account of medication as well as lifestyle changes [38]. Patients with severe cognitive impairment, hearing impairment, terminal illness and substitute patients were excluded.

Patients were recruited in primary care practices from two regions of Germany (Hamburg and Heidelberg and environs). A total of 889 primary care physicians in general practices were randomly selected and invited to take part in the study, of whom 36 (4%) agreed to participate. Primary care practices were asked to recruit patients over 65 years that had visited the practice within the last three months. All in all, 1243 patients were invited to take part in the study. Eligible patients received a letter signed by their primary care physician including the study materials (the information leaflet including contact details of the research team, a contact form and the declaration of consent).

The study was approved by the Ethics Committee of the Hamburg Medical School (PV5846), the Ethics Committee of the Medical Faculty of the Heidelberg University (S-665/2018) as well

as the Baden-Wuerttemberg regional medical board (B-F-2018-096). The study has been registered at the German Clinical Trial Register prior to the start of the study (registration no. DRKS00015718).

The STROBE guideline was used for reporting this study.

Data collection

Data were collected via standardized, face-to-face interviews. Patients who were interested to participate in the study were requested to return the completed contact form and declaration of consent to be contacted by telephone by the research team. After a telephone appointment with potential participants, a member of the research team visited the participant at home or at the primary care practice. Patients were again informed about the study and gave written consent to participate directly before the interview. Standardized interviews based on a paper-based questionnaire were conducted between July 2019 and February 2020.

Measures

The questionnaire was read out to the patient and the response options for the validated measures were laid out on a card in front of the participant. Socio-demographic data including age, gender, marital status, education level, country of birth and native language were collected.

The outcome variable patient activation was measured with the 13-item validated version in German (PAM-13D). PAM-13D includes statements regarding patients' beliefs about health care, self-assessed knowledge, and confidence in their ability to manage their conditions [11, 12]. Each statement is rated by the individual participant on the response scale of 1 to 4 (German version) where 1 represents "*disagree strongly*" and 4 represents "*agree strongly*". To calculate PAM scores (ranging from 0 to 100), we used the standardised spreadsheet provided by the developers (Insignia Health), which transforms the German response options into standardized metrics. Higher scores indicate that the patient is more activated [39]. Patients can be classified based on their overall score into one out of four levels. Patient in level 1 may not understand their role in decision-making about their health and tend to be passive. Level 2 includes patients who may still lacking knowledge and confidence to manage their health. In level 3, patients are more active but may still struggle to manage all aspects of

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health behaviour. Patients in level 4 can manage their health but may not be able to stay the course under stress [39].

To assess patients’ experiences of primary care, we asked them a set of different questions relating to domains of high-quality care. The domains were derived from a systematic review of guidelines, focus groups with patients with multimorbidity and their relatives and selected and consented by an expert panel. They are suggested as indicators for the quality of care for patients with multimorbidity and could be used as measures to establish specific quality improvements [35, 36]. Domains of care covered were a) preferences in treatment b) treatment goals, c) involvement in treatment, d) patient training programme e) support group f) self-management plan, g) medication plan, h) review on medication, i) information on medication and j) discussion about their treatment burden. The questions had mostly three response options (*yes, no and I do not know*). Response options for the question concerning involvement in care (c) were ‘*always*’ or ‘*usually*’/ ‘*rarely*’/ ‘*never*’. All answers/items were dichotomized.

Statistical analysis

Descriptive statistics were calculated for all variables included in the analysis to examine means, standard deviation, distribution for continuous variables, and frequencies for categorical data. A regression analysis was performed in order to assess potential effect of patients’ experiences of primary care on patient activation. PAM score was treated as the dependent variable whereas the reported patients’ experiences of primary care were treated as independent variables. Due to the hierarchical structure of the data, the regression analysis was based on a linear multilevel model with a random intercept for primary care practices in which patients were nested. In the analysis, we controlled for patients’ age and gender. The linear model was chosen due to the approximately normal distribution of the residuals in the Q-Q-Plot. Nevertheless, since the PAM scores were predominantly in the high activation group, we additionally performed an ordinal logistic regression with the PAM Level as the dependent variable. In all analyses, $p < 0.05$ was considered significant. Multicollinearity analysis showed variance inflation factors of less than 1.4, therefore multicollinearity did not pose a substantial problem [40]. We used IBM SPSS version 25.0 for statistical analysis, except for the post-hoc power analysis, which was performed with G-Power. Data where PAM score or level was missing was excluded from the analysis.

Patient and public involvement

Patient representatives were involved in the rating and selection of QI, here referred to as domains of patients' experiences. Apart from that, there was no patient or public involvement in the design, conduct and reporting of this study.

Results

Table 1: Characteristics of the study population

Sample characteristic	Sample description (n = 346)
Age, mean (SD)	77.4 (7.0)
Gender, n (%)	
- female	191 (55.2)
- male	155 (44.8)
Marital status, n (%)	
- married	189 (54.6)
- unmarried/ single	23 (6.6)
- divorced	34 (9.8)
- widowed	100 (28.9)
Living alone	
- Yes	124 (35.8)
- No	222 (64.2)
Country of birth, n (%)	
- Germany	320 (92.5)
- other country	26 (7.5)
Native language, n (%)	
- German	340 (99.1)
- other	3 (0.9)
CASMIN (educational classification) n (%)	
- level 1 (no/ low education level with/ without vocational training)	193 (56.1)
- level 2 (middle/ high education level with/ without vocational training)	96 (27.9)
- level 3 (high education level)	55 (16.0)
Employment situation, n (%)	
- Working	8 (2.3)
- Retired/not economically active	338 (97.7)
Nursing care dependency, n (%)	
- Yes	78 (22.5)
- No	268 (77.5)
Health insurance, n (%)	
- insured under a statutory insurance plan	324 (93.6)
- privately insured	22 (6.3)

(Self-reported) Chronic conditions, mean (SD)	9.9 (4.4)
(Self-reported) Medication, mean (SD)	6.9 (3.5)
Patient Activation Measure (PAM Score). mean (SD)	76.1 (16.4)
PAM Level n (%)	
- level 1 (≤ 47.0) (least activated)	13 (3.8)
- level 2 (≥ 47.1 and ≤ 55.1)	26 (7.5)
- level 3 (≥ 55.2 and ≤ 72.4)	94 (27.2)
- level 4 (≥ 72.5) (most activated)	210 (60.7)
- missing	3 (0.9)

Out of 1243 invited patients a total of 346 took part in the study (participation rate 27.8 %). First, we present the characteristics of the study sample (Table 1). Patients were, on average 77.4 (± 7) years old and predominantly born in Germany. Their educational qualification was relatively low with 55.8 % of the sample being in Level 1 of the Comparative Analysis of Social Mobility in Industrial Nations (CASMIN), including all respondents with elementary education with or without basic vocational qualification. Mostly all participants were retired or not economically active (97.7%) and reported on average of 9.9 (± 4.4) chronic conditions. Across all respondents, the mean PAM score was 76.1 with a median of 75, ranging from 22.6 to 100. Nearly two thirds of all participants had patient activation scores of 72.5 and higher (level 4). Exceedingly few participants reported lower activation scores (level 1 and 2). There was no significant difference in PAM scores between the two study sites.

Table 2: Influences from patients' experiences of primary care on PAM scores (multilevel model with a random intercept with patients nested within primary care practices)

	B (SE)	95 % CI	p
Age	-0.24 (0.21)	-0.66 to -0.17	0.224
Gender	2.65 (2.87)	-3.02 to 8.33	0.356
Did your primary physician ask you about your preferences in your treatment?	-0.33 (3.13)	-6.53 to 5.85	0.914
Have you agreed on treatment goals with your primary physician?	-0.29 (3.04)	-6.32 to 5.73	0.922
Do you feel as involved in decisions about your treatment as you would like to be?*	-8.56 (3.36)	-15.21 to -1.91	0.012*

Have you been offered participation in a patient training programme after your diagnosis?	-1.15 (3.52)	-8.12 to 5.82	0.744
Have you been offered the opportunity to participate in a support group after your diagnosis?	0.52 (4.62)	-8.63 to 9.68	0.910
Have you received a written (self-management) plan about what you can do to improve your health?	6.51 (3.30)	-0.02 to 13.06	0.051
Do you have a medication plan?*	-12.01 (5.83)	-23.55 to -0.48	0.041*
In your opinion is this medication plan up-to-date?	6.75 (5.16)	-3.46 to 16.97	0.194
Has your primary physician reviewed your medication with you in the last 12 months?	-1.86 (3.33)	-8.47 to 4.73	0.576
Has your primary physician explained to you how and when you should take the medication?	7.65 (4.37)	-0.99 to 16.31	0.083
Has your primary physician discussed with you how you cope with the burden of the chronic disease?	2.26 (3.22)	-4.11 to 8.64	0.484

Table 2 presents the results of the multilevel regression analysis. The domains 'involvement in treatment' and 'receiving a medication plan' showed significant effects in the multilevel model. The domain of 'receiving a self-management plan' was close to the significant threshold and thereby also considered as relevant. Controlling for age and gender, we found that patients who stated they were not always as involved in decisions about their treatment as far as they would want to, had lower scores on the measure of patient activation ($B = -8.56$, $p = 0.012$). These results indicate that, on average, a change of the response option from 'always' to 'usually/infrequent/never' was associated with an 8.56 decrease in a patient's reported level of activation. Furthermore, we found that patients who reported that they

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received a self-management plan from their primary care physician were more likely to have higher patient activation scores ($B= 6.51, p=0.051$). This indicates that if patients changed their response option from ‘yes’ to ‘no’, on average, the PAM score increased by 6.51 units. In contrast, if patients stated that they received an up-to-date medication plan from their primary care physician the patient activation scores decreased by 12.01 units ($p=0.041$) (Table 2). The results of the ordinal logistic regression can be found in supplemental file 1. In this analysis the same predictors showed significant associations with PAM levels in the same direction as in the multiple linear regression analysis. The post-hoc analysis with a moderate effect size of $f^2 = 0.13$ showed a statistical power of 99 %. Large and moderate effects could be identified. To point out small effects, a sample size of 1,283 patients would have been needed.

Discussion

The objective of this study was to analyse the association of patients’ experiences with primary care and patient activation among an older multimorbid population. Our results indicate that there are domains of primary care, which are associated with patient activation. Receiving written information on self-management tasks as well as involvement in care was found to be associated with higher patient activation scores. Receiving a medication plan was found to be associated with lower patient activation scores. Nevertheless, only three out of ten domains showed a significant association with patient activation.

Our findings on the distribution of PAM scores show that patients in this study were on average highly activated, which is inconsistent with the majority of existing studies on patient activation. Studies with a comparable sample of patients in age and diseases show mean PAM scores around about 60 [12, 23, 41]. However, there are studies with highly activated patients, for example Greene et al. [13] found 61.1 % in the highest activation level in a convenience sample of adults aged 65 and older. Furthermore, in an international comparison of psychometric properties and scores of PAM, German patients had the highest scores with a mean of 67.2 [42]. Even though such high scores are unexpected, one explanation may be that the standardised interviews took place in person, hence social desirability may be an impact. Participating population (both physicians and patients) were willing to participate in research, hence highly motivated. Thus, it seems quite likely that those were activated individuals with an interest in conversations about health and healthcare. Using the PAM as an outcome

measure carries the risk that high scores will be seen as 'better' and a linear increase in scores is expected [43]. However, previous research has shown that patients starting at a low activation score are more likely to increase activation [22]. In addition, patients can also shift between PAM levels if their condition or treatment changes. Moreover, it could also be a positive outcome for some patients to maintain their activation level rather than to increase it. Especially for older multimorbid patients with already high activation scores, as in our study, this could be the case. As so PAM scores in our study are predominantly in the high activated group, our results could serve as a basis of identifying patients experience elements which are associated with higher activation/ lower activation. Intervening on those elements might improve activation, but needs further testing.

Our findings are, for the most part, in line with the assumed conceptual model between shared decision making/ patient participation/ patient centeredness and patient activation and their link to positive health outcomes. The findings of patient's experiences with primary care could explain the connections.

Patients that were satisfied with the extent they were being involved in decisions also received higher results for patient activation. This suggests that fostering shared decision making and involvement from a passive role could be associated with changes in behaviours and attitudes among multimorbid patients. Our findings are supported by a study by Wensing et al. that examined patient enablement, a relating concept to patient activation and its association to involvement. They found that older patients in Europe who positively evaluated their involvement in primary care were more likely to be enabled, if the patient had a high preference for involvement the impact of evaluation on enablement was even higher. The authors concluded that improving patient evaluation of involvement in care may impact and enhance their enablement [44]. A clinical review on the management of multimorbid patients in primary care outlined that in the context of multimorbidity and shared decision making it is crucial to determine what matters most to the patient [4]. As the results of Castro et al. [10] present in their review "by focusing on patient participation as a strategy, a patient centered approach is facilitated which leads to patient empowerment" [10]. Our results indicate that some patients would like to be more involved in treatment, which may influence their activation level. However, it could also be likely that activated patients drive and determine shared decision making, as they have the knowledge and skills as well as the confidence to

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participate in their care. This assumption is supported by Poon et al. [7] , although they showed a stronger association between baseline PAM to follow-up shared decision making measure than the other way around [7]. A bidirectional association in our study is likely with activation influencing the involvement process but also fostering activation by involving the patient. Our study results show an association between patient involvement and patient activation but cannot show causality. Hence, it is possible that patient activation is cause or consequence of patient involvement. The direction of the relationship remains unclear.

It is surprising that the domains of the preferences in the treatment as well as treatment goal setting was not significant in the multilevel analysis, as they are also aspects of shared decision making and patient centered care. Related to treatment goal agreements, studies showed various results. Alexander et al. [28] declared that goal setting places major responsibility on patients, as they have to understand the specifics of the conditions and alternative therapy approaches.

Another unexpected result was the finding that PAM scores were lower if patients received an up-to-date medication plan. Previous studies have shown that patients with higher activation scores are more likely to adhere to medication plans [14–16]. An explanation for our results could be that patients without a medication plan might have fewer medication and therefore fewer chronic conditions. Thus, they are healthier. Moreover, it is very likely that the association is affected by other factors. Primary care physicians may be more likely to issue clear medications plans if they have concerns about a patient’s capacity to manage their medication, thus, patients that are less well activated or patients that share the responsibility for their care with other people e.g., family members. A written medication plan does not necessarily support patients’ autonomy in decision-making. An alternative explanation for our findings is that medication plans could support a more passive patient role.

In contrast, our data indicate a positive association between receiving a self-management plan and higher patient activation. Even though the domain is only close to the significant threshold ($p= 0.051$), we consider the domain relevant. It suggests that having a plan with instructions on self-management may be associated with higher activation. The interpretation is supported by the finding that patient activation is linked to positive changes in a variety of self-management behaviour, like doing exercises, managing stress or reading about the side effects of new medication [17]. Another unexpected finding is that the offer to participate in

patient training programmes or support groups showed no significant effect, while several aspects of patient education programs have been found to have a positive impact on patient activation [45]. Again, we are not able to draw conclusions concerning the direction of associations between the domains of receiving a medication plan or a self-management plan and patient activation.

The domain of the information on new medication is also close to the significant threshold ($p=0.083$) and thereby may also be a relevant domain for primary care physicians to consider for enhancing patient activation. Explaining and discussing new prescriptions is an important step in involving patients actively in their care. These results are in line with a study by Hibbard et al. [17] that higher patient activation scores were associated with reading about side effects when taking new medication.

We found no significant association between patient activation and discussions on coping with the burden of the disease. Research on associations between patient activation and treatment burden is rare. A large cohort study in UK did not find an association on patient activation and perceived impact of multimorbidity [23], whereas a recent study among patients with chronic kidney disease found higher symptom burden in patients with lower activation scores [46]. In the German guideline for multimorbidity, primary care physicians are encouraged to reduce the burden of treatment as well as to discuss it with their patients [47]. However, to discuss treatment burden may also be a difficult issue for physicians as well as for patients. Previous research has demonstrated a 4-6-point difference on the PAM scale in the comparison of different patients as practically meaningful [17, 27, 48, 49]. This undermines the practical relevance of our results on patients' experiences of primary care and its association to patient activation. Given the wide usage and the potential patient activation has been shown on health-related outcomes in other countries as well as the sparse research on this subject in Germany, our findings could help identifying the patient experience elements associated with higher activation. Intervening on those elements might improve activation but needs further research.

Strengths and limitations

Our results are limited by the cross-sectional design, which precludes making casual inferences about the relationship between patients' experiences of primary care, shared decision-making and patient activation. The results should be seen under the fact that our

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study population consisted of a heterogenous group of people with different diseases and at different stages of their diseases. Moreover, several factors concerning patients’ experiences with primary care were included. Since the purpose was to investigate the experiences of primary care and its association with patient activation, we did not analyse the direct impact of different comorbidities or medication on patient activation and the analysis was only controlled for patient characteristics of age and gender. However, our results could provide an initial assessment of patient experiences and associations with patient activation.

Conclusion

In our examination of older patients with multimorbidity, there was a higher level of patient activation among patients who experienced involvement in their care as they wished and those who had self-management plans. Among patients with medication plans, activation was lower. Only three out of ten patient experience domains showed an association with patient activation. Associations in patient activation with involvement in care, self-management plans and medication plans are a first step that require further clarification, testing and qualitative exploration in the field of patients’ experiences and patient activation. Understanding the factors regarding patients’ experiences of primary care practices and the association with patient activation may help primary physicians to enhance involvement, shared decision-making and thereby activation of their patients. Efforts to improve involvement should focus on the individual patient as well as on the aspects proceeding in primary care practices and the relationship of patients and their primary care physicians. Primary care patients should direct their attention at asking their multimorbid patients to what extent they want to be involved in their care, if they want to set up self-management tasks in a written plan as well as to explain and discuss the prescription of medication. Further analysis of longitudinal studies will be necessary to gain insight into the causal relationship between patient activation, shared decision-making and patients’ experiences of primary care.

Data availability statement

No data are available, as the ethics approval does not allow data sharing.

Ethics declaration

The study was approved by the Ethics Committee of the Hamburg Medical School (PV5846), the Ethics Committee of the Medical Faculty of the Heidelberg University (S-665/2018) as well as the Baden-Wuerttemberg regional medical board (B-F-2018-096).

Author contributions

MS, JSz contributed to the conception and design of the study. AB, KG and JS collected the data. DL, IS supervised the project. MW supervised the work. AB performed data analysis and drafted the manuscript. AB, MW, DL, KG, JS contributed to the interpretation of the results. All authors critically revised the draft and approved submission of the final version.

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Conflicts of interest

None.

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Figure legend

Figure 1: Conceptual model: interaction between shared decision making/patient participation/patient centeredness and patient activation, adapted from Castro et al. [10].

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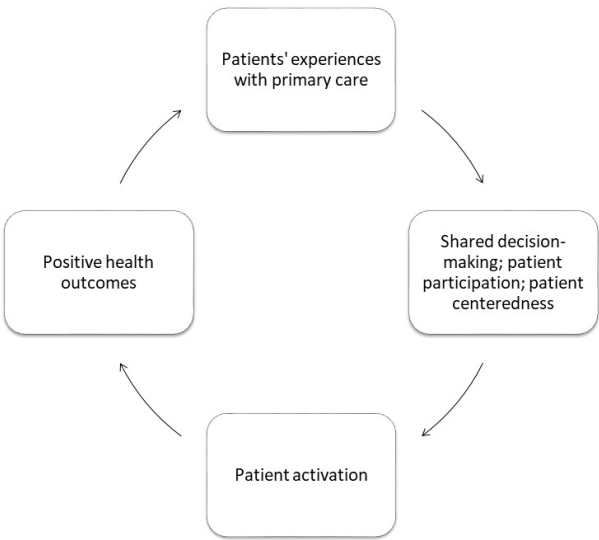


Figure 1: Conceptual model: interaction between shared decision making/patient participation/patient centeredness and patient activation, adapted from Castro et al. [10].

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Supplemental material

Appendix to: **Experiences of patients with multimorbidity with primary care and the association with patient activation: a cross-sectional study in Germany**

Results of the ordinal logistic regression analysis

	B (SE)	95 % CI	p
Age	-0.32 (0.02)	-0.08 to -0.02	0.239
Gender	-0.17 (0.37)	-0.92 to 0.56	0.637
Did your primary physician ask you about your preferences in your treatment?	0.27 (0.39)	-0.49 to 1.04	0.484
Have you agreed on treatment goals with your primary physician?	0.63 (0.39)	-0.14 to 1.47	0.111
<i>Do you feel as involved in decisions about your treatment as you would like to be?*</i>	0.89 (0.41)	0.08 to 1.70	0.030*
Have you been offered participation in a patient training programme after your diagnosis?	0.44 (0.46)	-0.47 to 1.35	0.347
Have you been offered the opportunity to participate in a support group after your diagnosis?	-0.71 (0.66)	-2.03 to 0.59	0.283
<i>Have you received a written (self-management) plan about what you can do to improve your health?*</i>	-1.21 (0.48)	-2.16 to -0.25	0.013*
Do you have a medication plan?	1.36 (0.73)	-0.07 to 2.80	0.062
In your opinion is this medication plan up-to-date?	-1.23 (0.63)	-2.47 to 0.00	0.051
Has your primary physician reviewed your medication with you in the last 12 months?	0.42 (0.44)	-0.44 to 1.30	0.340
Has your primary physician explained to you how and when you should take the medication?	-0.81 (0.53)	-1.86 to 0.23	0.127

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Has your primary physician discussed with you how you cope with the burden of the chronic disease?	-0.69 (0.44)	-1.56 to 0.17	0.116
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Note: * significant associations with patient activation level

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Reporting checklist for cross sectional study.

Based on the STROBE cross sectional guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the STROBE cross sectional reporting guidelines, and cite them as:

von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The Strengthening of Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies.

			Page
Reporting Item			Number
Title and abstract			
Title	#1a	Indicate the study's design with a commonly used term in the title or the abstract	1

1	Abstract	#1b	Provide in the abstract an informative and balanced	2
2			summary of what was done and what was found	
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6	Introduction			
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9	Background /	#2	Explain the scientific background and rationale for the	3- 6 5
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14	Objectives	#3	State specific objectives, including any prespecified	6 5
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19	Methods			
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23	Study design	#4	Present key elements of study design early in the paper	5 - 6 - 7
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26	Setting	#5	Describe the setting, locations, and relevant dates,	5 - 6 - 7
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34	Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of	5 - 6 - 7
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47	Data sources /	#8	For each variable of interest give sources of data and	5 - 7 -8
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Bias	#9	Describe any efforts to address potential sources of bias	7-8
Study size	#10	Explain how the study size was arrived at	6
Quantitative variables	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	7- 98
Statistical methods	#12a	Describe all statistical methods, including those used to control for confounding	7- 98
Statistical methods	#12b	Describe any methods used to examine subgroups and interactions	7- 98
Statistical methods	#12c	Explain how missing data were addressed	9
Statistical methods	#12d	If applicable, describe analytical methods taking account of sampling strategy	Not applicable
Statistical methods	#12e	Describe any sensitivity analyses	8-9
Results			
Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	8-9 6-10

1	Participants	#13b	Give reasons for non-participation at each stage	<u>Not</u>
2				<u>applicable</u>
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6	Participants	#13c	Consider use of a flow diagram	<u>Not</u>
7				<u>applicable</u>
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11	Descriptive data	#14a	Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders. Give information separately for exposed and unexposed groups if applicable.	<u>9-108-9</u>
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21	Descriptive data	#14b	Indicate number of participants with missing data for each variable of interest	<u>10</u>
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27	Outcome data	#15	Report numbers of outcome events or summary measures. Give information separately for exposed and unexposed groups if applicable.	<u>10</u>
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35	Main results	#16a	Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	<u>109-11</u>
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45	Main results	#16b	Report category boundaries when continuous variables were categorized	<u>10</u>
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50	Main results	#16c	If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	<u>Not</u>
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55	Other analyses	#17	Report other analyses done—e.g., analyses of subgroups and interactions, and sensitivity analyses	<u>8-9</u>
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Discussion

Key results	#18	Summarise key results with reference to study objectives	124
Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	164
Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	124-164
Generalisability	#21	Discuss the generalisability (external validity) of the study results	124-164
Other Information			
Funding	#22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	185

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BMJ Open

Experiences of patients with multimorbidity with primary care and the association with patient activation: a cross-sectional study in Germany

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Experiences of patients with multimorbidity with primary care and the association with patient activation: a cross-sectional study in Germany

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Word count: 4449

Abstract

Objectives The present study aimed to explore the association between patient activation and patients’ experience of care among an elderly multimorbid population in Germany.

Design Cross-sectional study.

Setting Primary care practices in two German settings.

Participants 346 patients with three or more chronic conditions aged 65 years and over from 36 primary care practices.

Outcome measures Patient activation was measured with the Patient Activation Measure. To assess patient experiences with primary care, a set of questions concerning domains of primary care were included. Multilevel regression analyses were performed to examine which domains of care were associated with patient activation.

Results Out of 1243 invited patients a total of 346 took part in the study (participation rate 27.8 %). Mean PAM-score was 76.1. Across all patients, 3.8 % achieved PAM level 1, 7.5 % level 2, 27.2 % level 3 and 60.7 % level 4. PAM scores suggest a highly activated patient group. In the regression analysis, three out ten domains of patients’ experiences showed an association with patient activation. The domains ‘being involved in decision as much as desired’ (B=-8.56, p=0.012) and ‘receiving a self-management plan’ (B=6.51, p=0.051) were associated with higher patient activation scores. Patients with an up-to-date medication plan had lower patient activation scores (B=-12.01, p=0.041).

Conclusion Specific domains of primary care were found to be associated with patient activation. To enhance patient activation, primary care physicians may increase involvement of patients in decisions. Future research should examine the causality of these associations.

Trial registration number

German clinical trials registry (DRKS00015718).

Key words Multimorbidity, Patient activation, Patient reported outcomes, Primary Care, Germany

Article summary

Strengths and limitations of this study

- Patients with various combinations of chronic diseases were surveyed in standardized interviews.
- Several factors concerning patient experiences with primary care were included in the multivariate analysis.
- Due to the cross-sectional design, we are not able making casual inferences about the relationship between patients' experiences of primary care, shared decision-making and patient activation.

Introduction:

About 62 % of patients aged 65 years or higher in Germany have three or more chronic conditions, which is defined as multimorbidity [1]. Multimorbidity is associated with higher healthcare utilisation and costs, lower quality of life and higher mortality [2, 3]. This has consequences not only for the patient but for the daily work of primary care physicians, whom are the main contact point of older multimorbid patients [4]. It is widely recognised that engaging patients in their own care is critical for successful health care systems as well as a crucial part in patient-centred care [5]. As described in the chronic care model by Wagner et al., it is assumed that *"interactions between practice team and patients that consistently provide the assessments, support for self-management, optimization of therapy, and follow-up are associated with good outcomes and leads to high-quality chronic illness care"* [6]. Patient activation highlights patients' willingness and ability to manage their health and care independently [5]. Shared decision-making, a key element in patient-centred care, gives patients the opportunity to participate and engage in their own health. Studies indicated that shared decision-making results in patient activation and self-management which in turn can result in better health outcomes [7, 8]. Therefore, active participation and self-management of patients is a crucial part in primary care, especially in patients with multimorbidity [6, 9]. Figure 1 shows the assumed process association of shared decision-making and patient activation in this study. We assume that patient activation is an intrinsic characteristic which can be fostered by support such as shared decision making or patient centeredness. This is

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supported by the process model of Castro et al. [10] for the concepts of patient participation, patient-centeredness and patient empowerment, whereby patient activation is an attribute of patient empowerment [10]. The model declares that by “focusing on patient participation as a strategy, a patient centered approach is facilitated which leads to patient empowerment.”

The patient activation measure (PAM) is a 13 item questionnaire developed by Hibbard et al. in 2005 that focuses on *“knowledge, skills and confidence that equip patients to become actively engaged in their own health”* [11], [12, 13]. The measure has been widely used to measure the level of empowerment and self-management of chronically ill patients. PAM is based on the constructs self-efficacy, behaviour of change and knowledge of control. Its goal is to identify the level of activation of individuals, thus, to support them in their healthcare and health-related behaviour according to their level. Tailoring care according to the level of activation may have positive effects on different health outcomes [11]. The developers have shown that higher levels of PAM are related to lower probability of emergency department (ED) visits, being obese or smoking, and a higher probability of seeking cancer screening and other recommended clinical procedures [11]. Other studies concluded that patients with higher levels of PAM are more likely to adhere to medical regimens, manage their chronic conditions, and less likely to be hospitalized [14–16]. Change in patient activation is related to positive changes in a variety of self-management behaviours, like doing physical exercises, managing stress or reading about side effects when taking new medication [17]. Furthermore, higher patient activation scores are associated with lower health care costs [18]. Some studies looking at different interventions like online programs or walking interventions over a period of time showed that patient activation may be changeable[19–21]

Thus, there are many studies reporting the association of patient activation with clinical outcomes and health-related behaviour. Therefore, it would be helpful to identify which aspects that can be directly addressed by primary care physicians are linked to higher patient activation. Studies have shown that satisfaction with healthcare and primary care physicians contributed to higher patient activation scores [22–24]. Hibbard and colleagues found that patients whose physicians helped to monitor their health and set goals had higher patient activation scores [12]. Additionally, patients who trust their primary care physician had also higher scores [11, 25, 26]. A study examining the association of patient-physician relationship

with patient activation among chronically ill patients found four relevant aspects [27]. Patients that report higher quality of interpersonal exchanges with their physicians, being treated fair and respectful and had more frequent communication with physicians outside the consultation hours were associated with higher levels of PAM. Treatment goal setting in this study was not associated with PAM [27]. Another study pointed out that primary care providers who were convinced of patients' role of self-management correlated positively with higher PAM scores in their patients [28]. The primary care providers' beliefs of the importance on patients' role were moderately positively correlated with a change in activation scores of patients [28]. Furthermore, patient activation and the concept of shared-decision making, in which patients and physicians exchange information about patient preferences and treatment options in a collaborative process [29], are known to be associated [7]. Especially in the area of patient activation and patient experiences of care longitudinal studies are rare [5], making it impossible to draw conclusions on the direction of causality. However, one study examined the relationship between changes in activation over three years and patient-assessed quality of chronic illness care among patients with type 2 diabetes. They showed that patient activation and patient-assessed quality of chronic illness care change in the same direction. The authors recommend to compare quality assessments within patient activation levels [30]. Moreover, a study from the authors of the PAM on approaches used by primary care providers whose patients had an increased activation level revealed five key strategies: They supported patient behaviour changes by emphasising patients' self-responsibility but also showing that they care for their concerns and working in partnership with their patients. Also identifying small steps and scheduling frequent follow-up visits to celebrate successes or solve problems were reported. Providers whose patients had lesser change in activation were far less likely to describe using these approaches [31].

Although patient activation and its associations has been studied extensively [11], the evidence regarding patient experiences with primary care and its association to patient activation is mainly from North America and largely over a decade old. Furthermore, only few studies focused on older patients with multimorbidity [22–24].

Germany's healthcare system is characterized by a number of unique features such as universal coverage through health insurance, prominent role of physicians (rather than nurses and others), frequent (short) contacts to the primary care physician, and emphasis on internal

medicine in the vocational training of primary care physicians [32, 33]. Therefore, it is uncertain whether the findings of previous studies on patient activation can be generalized to the primary care setting among multimorbid patients in Germany. Thus, the aim of this study was to identify which patients’ experiences regarding primary care are associated with patient activation among a population of older patients with multimorbidity in Germany.

Methods

Study design and population

This study had a cross-sectional design. Data was collected as part of the project *Development and Validation of Quality Indicators for Multimorbidity* (MULTIqual), which aims at developing a set of indicators for primary care providers for patients with multimorbidity [34, 35].

Eligible participants were patients aged 65 years or older with three or more chronic conditions. The conditions were: anaemia, diabetes mellitus, obesity, depression, anxiety disorder, Parkinson’s disease, mono- and polyneuropathy, vertigo, chronic ischaemic heart disease, angina pectoris, heart failure, peripheral artery disease (PAD), atherosclerosis, asthma, chronic obstructive pulmonary disease (COPD), chronic bronchitis, arthrosis, osteoporosis, urinary incontinence, malignant tumours. The list is derived from a previous study in Germany regarding patterns of multimorbidity [36]. These conditions were chosen as they impose symptom burden on patients and are accompanied with taking a considerable account of medication as well as lifestyle changes [37]. Patients with severe cognitive impairment, hearing impairment, terminal illness and substitute patients were excluded.

Patients were recruited in primary care practices from two regions of Germany (Hamburg and Heidelberg and environs). A total of 889 primary care physicians in general practices were randomly selected and invited to take part in the study, of whom 36 (4%) agreed to participate. Primary care practices were asked to recruit patients over 65 years that had visited the practice within the last three months. All in all, 1243 patients were invited to take part in the study. Eligible patients received a letter signed by their primary care physician including the study materials (the information leaflet including contact details of the research team, a contact form and the declaration of consent).

The study was approved by the Ethics Committee of the Hamburg Medical School (PV5846), the Ethics Committee of the Medical Faculty of the Heidelberg University (S-665/2018) as well

as the Baden-Wuerttemberg regional medical board (B-F-2018-096). The study has been registered at the German Clinical Trial Register prior to the start of the study (registration no. DRKS00015718).

The STROBE guideline was used for reporting this study.

Data collection

Data were collected via standardized, face-to-face interviews. Patients who were interested to participate in the study were requested to return the completed contact form and declaration of consent to be contacted by telephone by the research team. After a telephone appointment with potential participants, a member of the research team visited the participant at home or at the primary care practice. Patients were again informed about the study and gave written consent to participate directly before the interview. Standardized interviews based on a paper-based questionnaire were conducted between July 2019 and February 2020.

Measures

The questionnaire was read out to the patient and the response options for the validated measures were laid out on a card in front of the participant. Socio-demographic data including age, gender, marital status, education level, country of birth and native language were collected.

The outcome variable patient activation was measured with the 13-item validated version in German (PAM-13D). PAM-13D includes statements regarding patients' beliefs about health care, self-assessed knowledge, and confidence in their ability to manage their conditions [11, 12]. Each statement is rated by the individual participant on the response scale of 1 to 4 (German version) where 1 represents "*disagree strongly*" and 4 represents "*agree strongly*". To calculate PAM scores (ranging from 0 to 100), we used the standardised spreadsheet provided by the developers (Insignia Health), which transforms the German response options into standardized metrics. Higher scores indicate that the patient is more activated [38]. Patients can be classified based on their overall score into one out of four levels. Patient in level 1 may not understand their role in decision-making about their health and tend to be passive. Level 2 includes patients who may still lacking knowledge and confidence to manage their health. In level 3, patients are more active but may still struggle to manage all aspects of

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health behaviour. Patients in level 4 can manage their health but may not be able to stay the course under stress [38].

To assess patients’ experiences of primary care, we asked them a set of different questions relating to domains of high-quality care. The domains were derived from a systematic review of guidelines, focus groups with patients with multimorbidity and their relatives and selected and consented by an expert panel. They are suggested as indicators for the quality of care for patients with multimorbidity and could be used as measures to establish specific quality improvements [34, 35]. Domains of care covered were a) preferences in treatment b) treatment goals, c) involvement in treatment, d) patient training programme e) support group f) self-management plan, g) medication plan, h) review on medication, i) information on medication and j) discussion about their treatment burden. The questions had mostly three response options (*yes, no and I do not know*). Response options for the question concerning involvement in care (c) were ‘*always*’ or ‘*usually*’/ ‘*rarely*’/ ‘*never*’. All answers/items were dichotomized.

Statistical analysis

Descriptive statistics were calculated for all variables included in the analysis to examine means, standard deviation, distribution for continuous variables, and frequencies for categorical data. A regression analysis was performed in order to assess potential effect of patients’ experiences of primary care on patient activation. PAM score was treated as the dependent variable whereas the reported patients’ experiences of primary care were treated as independent variables. Due to the hierarchical structure of the data, the regression analysis was based on a linear multilevel model with a random intercept for primary care practices in which patients were nested. In the analysis, we controlled for patients’ age and gender. The linear model was chosen due to the approximately normal distribution of the residuals in the Q-Q-Plot. Nevertheless, since the PAM scores were predominantly in the high activation group, we additionally performed an ordinal logistic regression with the PAM Level as the dependent variable. In all analyses, $p < 0.05$ was considered significant. Multicollinearity analysis showed variance inflation factors of less than 1.4, therefore multicollinearity did not pose a substantial problem [39]. We used IBM SPSS version 25.0 for statistical analysis, except for the post-hoc power analysis, which was performed with G-Power. Data where PAM score or level was missing was excluded from the analysis.

Patient and public involvement

Patient representatives were involved in the rating and selection of QI, here referred to as domains of patients' experiences. Apart from that, there was no patient or public involvement in the design, conduct and reporting of this study.

Results

Table 1: Characteristics of the study population

Sample characteristic	Sample description (n = 346)
Age, mean (SD)	77.4 (7.0)
Gender, n (%)	
- female	191 (55.2)
- male	155 (44.8)
Marital status, n (%)	
- married	189 (54.6)
- unmarried/ single	23 (6.6)
- divorced	34 (9.8)
- widowed	100 (28.9)
Living alone	
- Yes	124 (35.8)
- No	222 (64.2)
Country of birth, n (%)	
- Germany	320 (92.5)
- other country	26 (7.5)
Native language, n (%)	
- German	340 (99.1)
- other	3 (0.9)
CASMIN (educational classification) n (%)	
- level 1 (no/ low education level with/ without vocational training)	193 (56.1)
- level 2 (middle/ high education level with/ without vocational training)	96 (27.9)
- level 3 (high education level)	55 (16.0)
Employment situation, n (%)	
- Working	8 (2.3)
- Retired/not economically active	338 (97.7)
Nursing care dependency, n (%)	
- Yes	78 (22.5)
- No	268 (77.5)
Health insurance, n (%)	
- insured under a statutory insurance plan	324 (93.6)
- privately insured	22 (6.3)

(Self-reported) Chronic conditions, mean (SD)	9.9 (4.4)
(Self-reported) Medication, mean (SD)	6.9 (3.5)
Patient Activation Measure (PAM Score). mean (SD)	76.1 (16.4)
PAM Level n (%)	
- level 1 (≤ 47.0) (least activated)	13 (3.8)
- level 2 (≥ 47.1 and ≤ 55.1)	26 (7.5)
- level 3 (≥ 55.2 and ≤ 72.4)	94 (27.2)
- level 4 (≥ 72.5) (most activated)	210 (60.7)
- missing	3 (0.9)

Out of 1243 invited patients a total of 346 took part in the study (participation rate 27.8 %). First, we present the characteristics of the study sample (Table 1). Patients were, on average 77.4 (± 7) years old and predominantly born in Germany. Their educational qualification was relatively low with 55.8 % of the sample being in Level 1 of the Comparative Analysis of Social Mobility in Industrial Nations (CASMIN), including all respondents with elementary education with or without basic vocational qualification. Mostly all participants were retired or not economically active (97.7%) and reported on average of 9.9 (± 4.4) chronic conditions. Across all respondents, the mean PAM score was 76.1 with a median of 75, ranging from 22.6 to 100. Nearly two thirds of all participants had patient activation scores of 72.5 and higher (level 4). Exceedingly few participants reported lower activation scores (level 1 and 2). There was no significant difference in PAM scores between the two study sites.

Table 2: Influences from patients' experiences of primary care on PAM scores (multilevel model with a random intercept with patients nested within primary care practices)

	B (SE)	95 % CI	p
Age	-0.24 (0.21)	-0.66 to -0.17	0.224
Gender	2.65 (2.87)	-3.02 to 8.33	0.356
Did your primary physician ask you about your preferences in your treatment?	-0.33 (3.13)	-6.53 to 5.85	0.914
Have you agreed on treatment goals with your primary physician?	-0.29 (3.04)	-6.32 to 5.73	0.922
Do you feel as involved in decisions about your treatment as you would like to be?*	-8.56 (3.36)	-15.21 to -1.91	0.012*

Have you been offered participation in a patient training programme after your diagnosis?	-1.15 (3.52)	-8.12 to 5.82	0.744
Have you been offered the opportunity to participate in a support group after your diagnosis?	0.52 (4.62)	-8.63 to 9.68	0.910
Have you received a written (self-management) plan about what you can do to improve your health?	6.51 (3.30)	-0.02 to 13.06	0.051
Do you have a medication plan?*	-12.01 (5.83)	-23.55 to -0.48	0.041*
In your opinion is this medication plan up-to-date?	6.75 (5.16)	-3.46 to 16.97	0.194
Has your primary physician reviewed your medication with you in the last 12 months?	-1.86 (3.33)	-8.47 to 4.73	0.576
Has your primary physician explained to you how and when you should take the medication?	7.65 (4.37)	-0.99 to 16.31	0.083
Has your primary physician discussed with you how you cope with the burden of the chronic disease?	2.26 (3.22)	-4.11 to 8.64	0.484

Table 2 presents the results of the multilevel regression analysis. The domains 'involvement in treatment' and 'receiving a medication plan' showed significant effects in the multilevel model. The domain of 'receiving a self-management plan' was close to the significant threshold and thereby also considered as relevant. Controlling for age and gender, we found that patients who stated they were not always as involved in decisions about their treatment as far as they would want to, had lower scores on the measure of patient activation ($B = -8.56$, $p = 0.012$). These results indicate that, on average, a change of the response option from 'always' to 'usually/infrequent/never' was associated with an 8.56 decrease in a patient's reported level of activation. Furthermore, we found that patients who reported that they

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received a self-management plan from their primary care physician were more likely to have higher patient activation scores ($B= 6.51, p=0.051$). This indicates that if patients changed their response option from ‘yes’ to ‘no’, on average, the PAM score increased by 6.51 units. In contrast, if patients stated that they received an up-to-date medication plan from their primary care physician the patient activation scores decreased by 12.01 units ($p=0.041$) (Table 2). The results of the ordinal logistic regression can be found in supplemental file 1. In this analysis the same predictors showed significant associations with PAM levels in the same direction as in the multiple linear regression analysis. The post-hoc analysis with a moderate effect size of $f^2 = 0.13$ showed a statistical power of 99 %. Large and moderate effects could be identified. To point out small effects, a sample size of 1,283 patients would have been needed.

Discussion

The objective of this study was to analyse the association of patients’ experiences with primary care and patient activation among an older multimorbid population. Our results indicate that there are domains of primary care, which are associated with patient activation. Receiving written information on self-management tasks as well as involvement in care was found to be associated with higher patient activation scores. Receiving a medication plan was found to be associated with lower patient activation scores. Nevertheless, only three out of ten domains showed a significant association with patient activation.

Our findings on the distribution of PAM scores show that patients in this study were on average highly activated, which is inconsistent with the majority of existing studies on patient activation. Studies with a comparable sample of patients in age and diseases show mean PAM scores around about 60 [12, 22, 40]. However, there are studies with highly activated patients, for example Greene et al. [13] found 61.1 % in the highest activation level in a convenience sample of adults aged 65 and older. Furthermore, in an international comparison of psychometric properties and scores of PAM, German patients had the highest scores with a mean of 67.2 [41]. Even though such high scores are unexpected, one explanation may be that the standardised interviews took place in person, hence social desirability may be an impact. Participating population (both physicians and patients) were willing to participate in research, hence highly motivated. Thus, it seems quite likely that those were activated individuals with an interest in conversations about health and healthcare. Using the PAM as an outcome

measure carries the risk that high scores will be seen as 'better' and a linear increase in scores is expected [42]. However, previous research has shown that patients starting at a low activation score are more likely to increase activation [21]. In addition, patients can also shift between PAM levels if their condition or treatment changes. Moreover, it could also be a positive outcome for some patients to maintain their activation level rather than to increase it. Especially for older multimorbid patients with already high activation scores, as in our study, this could be the case. As so PAM scores in our study are predominantly in the high activated group, our results could serve as a basis of identifying patients experience elements which are associated with higher activation/ lower activation. Intervening on those elements might improve activation, but needs further testing.

Our findings are, for the most part, in line with the assumed conceptual model between shared decision making/ patient participation/ patient centeredness and patient activation and their link to positive health outcomes. The findings of patient's experiences with primary care could explain the connections.

Patients that were satisfied with the extent they were being involved in decisions also received higher results for patient activation. This suggests that fostering shared decision making and involvement from a passive role could be associated with changes in behaviours and attitudes among multimorbid patients. Our findings are supported by a study by Wensing et al. that examined patient enablement, a relating concept to patient activation and its association to involvement. They found that older patients in Europe who positively evaluated their involvement in primary care were more likely to be enabled, if the patient had a high preference for involvement the impact of evaluation on enablement was even higher. The authors concluded that improving patient evaluation of involvement in care may impact and enhance their enablement [43]. A clinical review on the management of multimorbid patients in primary care outlined that in the context of multimorbidity and shared decision making it is crucial to determine what matters most to the patient [4]. As the results of Castro et al. [10] present in their review "by focusing on patient participation as a strategy, a patient centered approach is facilitated which leads to patient empowerment" [10]. Our results indicate that some patients would like to be more involved in treatment, which may influence their activation level. However, it could also be likely that activated patients drive and determine shared decision making, as they have the knowledge and skills as well as the confidence to

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participate in their care. This assumption is supported by Poon et al. [7] , although they showed a stronger association between baseline PAM to follow-up shared decision making measure than the other way around [7]. A bidirectional association in our study is likely with activation influencing the involvement process but also fostering activation by involving the patient. Our study results show an association between patient involvement and patient activation but cannot show causality. Hence, it is possible that patient activation is cause or consequence of patient involvement. The direction of the relationship remains unclear.

It is surprising that the domains of the preferences in the treatment as well as treatment goal setting was not significant in the multilevel analysis, as they are also aspects of shared decision making and patient centered care. Related to treatment goal agreements, studies showed various results. Alexander et al. [27] declared that goal setting places major responsibility on patients, as they have to understand the specifics of the conditions and alternative therapy approaches.

Another unexpected result was the finding that PAM scores were lower if patients received an up-to-date medication plan. Previous studies have shown that patients with higher activation scores are more likely to adhere to medication plans [14–16]. An explanation for our results could be that patients without a medication plan might have fewer medication and therefore fewer chronic conditions. Thus, they are healthier. Moreover, it is very likely that the association is affected by other factors. Primary care physicians may be more likely to issue clear medications plans if they have concerns about a patient’s capacity to manage their medication, thus, patients that are less well activated or patients that share the responsibility for their care with other people e.g., family members. A written medication plan does not necessarily support patients’ autonomy in decision-making. An alternative explanation for our findings is that medication plans could support a more passive patient role.

In contrast, our data indicate a positive association between receiving a self-management plan and higher patient activation. Even though the domain is only close to the significant threshold ($p= 0.051$), we consider the domain relevant. It suggests that having a plan with instructions on self-management may be associated with higher activation. The interpretation is supported by the finding that patient activation is linked to positive changes in a variety of self-management behaviour, like doing exercises, managing stress or reading about the side effects of new medication [17]. Another unexpected finding is that the offer to participate in

patient training programmes or support groups showed no significant effect, while several aspects of patient education programs have been found to have a positive impact on patient activation [44]. Again, we are not able to draw conclusions concerning the direction of associations between the domains of receiving a medication plan or a self-management plan and patient activation.

The domain of the information on new medication is also close to the significant threshold ($p=0.083$) and thereby may also be a relevant domain for primary care physicians to consider for enhancing patient activation. Explaining and discussing new prescriptions is an important step in involving patients actively in their care. These results are in line with a study by Hibbard et al. [17] that higher patient activation scores were associated with reading about side effects when taking new medication.

We found no significant association between patient activation and discussions on coping with the burden of the disease. Research on associations between patient activation and treatment burden is rare. A large cohort study in UK did not find an association on patient activation and perceived impact of multimorbidity [22], whereas a recent study among patients with chronic kidney disease found higher symptom burden in patients with lower activation scores [45]. In the German guideline for multimorbidity, primary care physicians are encouraged to reduce the burden of treatment as well as to discuss it with their patients [46]. However, to discuss treatment burden may also be a difficult issue for physicians as well as for patients. Previous research has demonstrated a 4-6-point difference on the PAM scale in the comparison of different patients as practically meaningful [17, 26, 47, 48]. This undermines the practical relevance of our results on patients' experiences of primary care and its association to patient activation. Given the wide usage and the potential patient activation has been shown on health-related outcomes in other countries as well as the sparse research on this subject in Germany, our findings could help identifying the patient experience elements associated with higher activation. Intervening on those elements might improve activation but needs further research.

Strengths and limitations

Our results are limited by the cross-sectional design, which precludes making casual inferences about the relationship between patients' experiences of primary care, shared decision-making and patient activation. The results should be seen under the fact that our

study population consisted of a heterogenous group of people with different diseases and at different stages of their diseases. Moreover, several factors concerning patients’ experiences with primary care were included. Since the purpose was to investigate the experiences of primary care and its association with patient activation, we did not analyse the direct impact of different comorbidities or medication on patient activation and the analysis was only controlled for patient characteristics of age and gender. However, our results could provide an initial assessment of patient experiences and associations with patient activation.

Conclusion

In our examination of older patients with multimorbidity, there was a higher level of patient activation among patients who experienced involvement in their care as they wished and those who had self-management plans. Among patients with medication plans, activation was lower. Only three out of ten patient experience domains showed an association with patient activation. Associations in patient activation with involvement in care, self-management plans and medication plans are a first step that require further clarification, testing and qualitative exploration in the field of patients’ experiences and patient activation. Understanding the factors regarding patients’ experiences of primary care practices and the association with patient activation may help primary physicians to enhance involvement, shared decision-making and thereby activation of their patients. Efforts to improve involvement should focus on the individual patient as well as on the aspects proceeding in primary care practices and the relationship of patients and their primary care physicians. Primary care practitioners should direct their attention at asking their multimorbid patients to what extent they want to be involved in their care, if they want to set up self-management tasks in a written plan as well as to explain and discuss the prescription of medication. Further analysis of longitudinal studies will be necessary to gain insight into the causal relationship between patient activation, shared decision-making and patients’ experiences of primary care.

Data availability statement

No data are available, as the ethics approval does not allow data sharing.

Ethics declaration

The study was approved by the Ethics Committee of the Hamburg Medical School (PV5846), the Ethics Committee of the Medical Faculty of the Heidelberg University (S-665/2018) as well as the Baden-Wuerttemberg regional medical board (B-F-2018-096).

Author contributions

MS, JSz contributed to the conception and design of the study. AB, KG and JS collected the data. DL, IS supervised the project. MW supervised the work. AB performed data analysis and drafted the manuscript. AB, MW, DL, KG, JS contributed to the interpretation of the results. All authors critically revised the draft and approved submission of the final version.

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Conflicts of interest

None.

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Figure legend

Figure 1: Conceptual model: interaction between shared decision making/patient participation/patient centeredness and patient activation, adapted from Castro et al. [10].

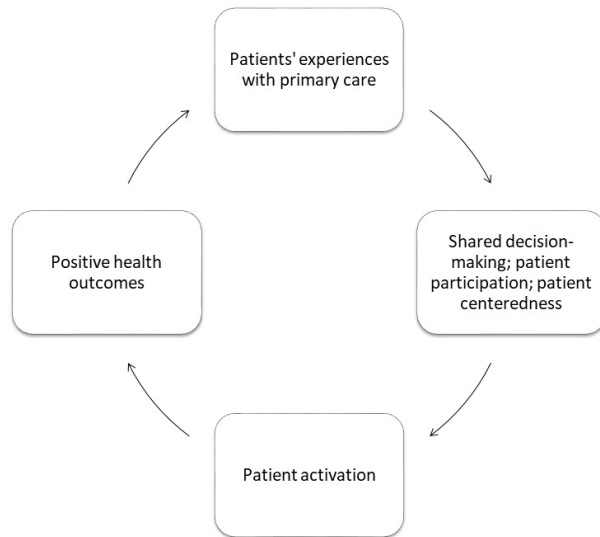


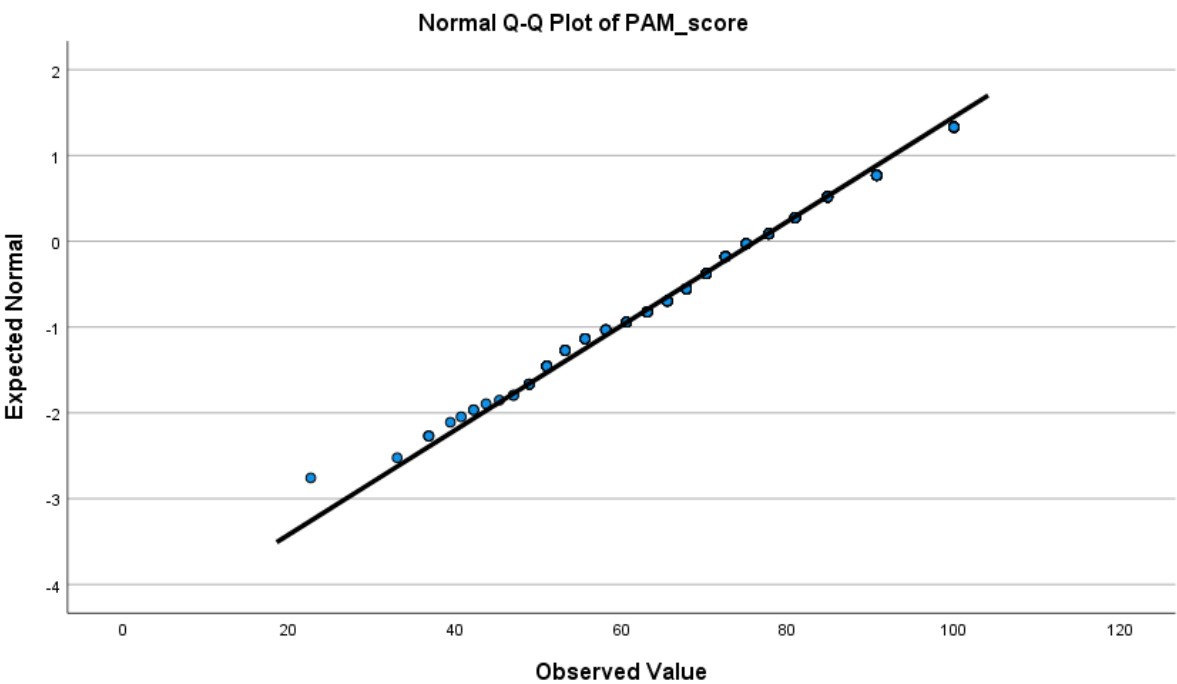
Figure 1: Conceptual model: interaction between shared decision making/patient participation/patient centeredness and patient activation, adapted from Castro et al. [10].

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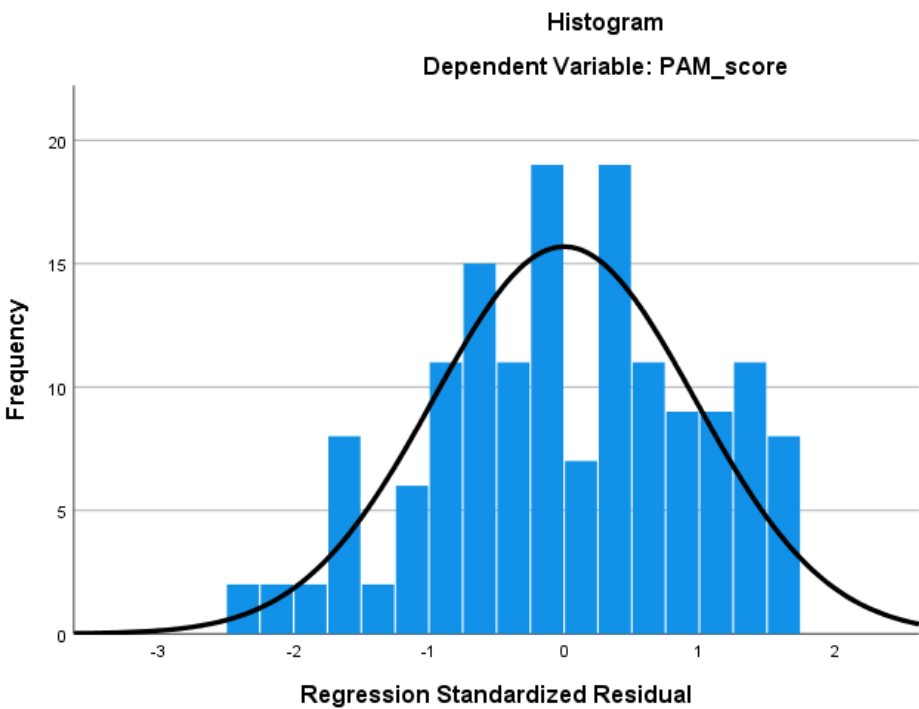
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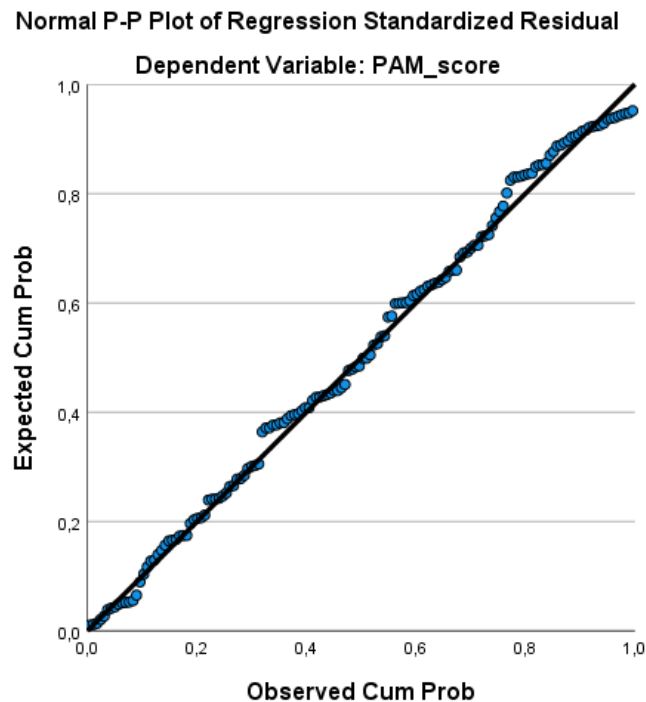
Appendix to: **Experiences of patients with multimorbidity with primary care and the association with patient activation: a cross-sectional study in Germany**

Analysis – Diagrams for the Linear model



Residuen:





Results of the ordinal logistic regression analysis

	B (SE)	95 % CI	p
Age	-0.32 (0.02)	-0.08 to -0.02	0.239
Gender	-0.17 (0.37)	-0.92 to 0.56	0.637
Did your primary physician ask you about your preferences in your treatment?	0.27 (0.39)	-0.49 to 1.04	0.484
Have you agreed on treatment goals with your primary physician?	0.63 (0.39)	-0.14 to 1.47	0.111
<i>Do you feel as involved in decisions about your treatment as you would like to be?*</i>	0.89 (0.41)	0.08 to 1.70	0.030*
Have you been offered participation in a patient training programme after your diagnosis?	0.44 (0.46)	-0.47 to 1.35	0.347
Have you been offered the opportunity to participate in a support group after your diagnosis?	-0.71 (0.66)	-2.03 to 0.59	0.283

Have you received a written (self-management) plan about what you can do to improve your health?*	-1.21 (0.48)	-2.16 to -0.25	0.013*
Do you have a medication plan?	1.36 (0.73)	-0.07 to 2.80	0.062
In your opinion is this medication plan up-to-date?	-1.23 (0.63)	-2.47 to 0.00	0.051
Has your primary physician reviewed your medication with you in the last 12 months?	0.42 (0.44)	-0.44 to 1.30	0.340
Has your primary physician explained to you how and when you should take the medication?	-0.81 (0.53)	-1.86 to 0.23	0.127
Has your primary physician discussed with you how you cope with the burden of the chronic disease?	-0.69 (0.44)	-1.56 to 0.17	0.116

Note: * significant associations with patient activation level

Reporting checklist for cross sectional study.

Based on the STROBE cross sectional guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the STROBE cross sectional reporting guidelines, and cite them as:

von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. The Strengthening of Reporting of Observational Studies in Epidemiology (STROBE) Statement: guidelines for reporting observational studies.

			Page
Reporting Item			Number
Title and abstract			
Title	#1a	Indicate the study's design with a commonly used term in the title or the abstract	1

1	Abstract	#1b	Provide in the abstract an informative and balanced	2
2			summary of what was done and what was found	
3				
4				
5				
6	Introduction			
7				
8				
9				
10	Background /	#2	Explain the scientific background and rationale for the	3- 6 5
11	rationale		investigation being reported	
12				
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14				
15	Objectives	#3	State specific objectives, including any prespecified	6 5
16			hypotheses	
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19				
20	Methods			
21				
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23	Study design	#4	Present key elements of study design early in the paper	5 - 6 - 7
24				
25				
26	Setting	#5	Describe the setting, locations, and relevant dates,	5 - 6 - 7
27			including periods of recruitment, exposure, follow-up, and	
28			data collection	
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34	Eligibility criteria	#6a	Give the eligibility criteria, and the sources and methods of	5 - 6 - 7
35			selection of participants.	
36				
37				
38				
39		#7	Clearly define all outcomes, exposures, predictors, potential	5 - 6 - 7 -8
40			confounders, and effect modifiers. Give diagnostic criteria,	
41			if applicable	
42				
43				
44				
45				
46				
47	Data sources /	#8	For each variable of interest give sources of data and	5 - 7 -8
48	measurement		details of methods of assessment (measurement). Describe	
49			comparability of assessment methods if there is more than	
50			one group. Give information separately for for exposed and	
51			unexposed groups if applicable.	
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Bias	#9	Describe any efforts to address potential sources of bias	7-8
Study size	#10	Explain how the study size was arrived at	6
Quantitative variables	#11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen, and why	7- 98
Statistical methods	#12a	Describe all statistical methods, including those used to control for confounding	7- 98
Statistical methods	#12b	Describe any methods used to examine subgroups and interactions	7- 98
Statistical methods	#12c	Explain how missing data were addressed	9
Statistical methods	#12d	If applicable, describe analytical methods taking account of sampling strategy	Not applicable
Statistical methods	#12e	Describe any sensitivity analyses	8-9
Results			
Participants	#13a	Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed. Give information separately for for exposed and unexposed groups if applicable.	8-9 6-10

1	Participants	#13b	Give reasons for non-participation at each stage	<u>Not</u>
2				<u>applicable</u>
3				
4				
5				
6	Participants	#13c	Consider use of a flow diagram	<u>Not</u>
7				<u>applicable</u>
8				
9				
10				
11	Descriptive data	#14a	Give characteristics of study participants (eg demographic,	<u>9-108-9</u>
12			clinical, social) and information on exposures and potential	
13			confounders. Give information separately for exposed and	
14			unexposed groups if applicable.	
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21	Descriptive data	#14b	Indicate number of participants with missing data for each	<u>10</u>
22			variable of interest	
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26	Outcome data	#15	Report numbers of outcome events or summary measures.	<u>10</u>
27			Give information separately for exposed and unexposed	
28			groups if applicable.	
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34	Main results	#16a	Give unadjusted estimates and, if applicable, confounder-	<u>109-11</u>
35			adjusted estimates and their precision (eg, 95% confidence	
36			interval). Make clear which confounders were adjusted for	
37			and why they were included	
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44	Main results	#16b	Report category boundaries when continuous variables	<u>10</u>
45			were categorized	
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49	Main results	#16c	If relevant, consider translating estimates of relative risk	<u>Not</u>
50			into absolute risk for a meaningful time period	<u>applicable</u>
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54	Other analyses	#17	Report other analyses done—e.g., analyses of subgroups	<u>8-9</u>
55			and interactions, and sensitivity analyses	
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Discussion

Key results	#18	Summarise key results with reference to study objectives	124
Limitations	#19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias.	164
Interpretation	#20	Give a cautious overall interpretation considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence.	124-164
Generalisability	#21	Discuss the generalisability (external validity) of the study results	124-164
Other Information			
Funding	#22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	185

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