








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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ABSTRACT

Objectives This 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 3 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 (PAM). 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 DRKS00015718.

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

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Patients with various combinations of chronic diseases were surveyed in standardised 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.

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 healthcare 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, optimisation 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

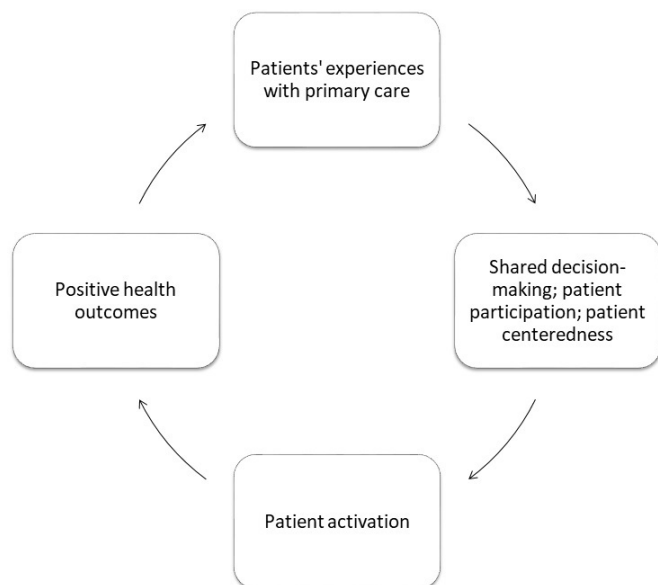


Figure 1 Conceptual model: interaction between shared decision making/patient participation/patient-centredness and patient activation, adapted from Castro *et al.*¹⁰

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-centredness. This is supported by the process model of Castro *et al.*¹⁰ for the concepts of patient participation, patient-centredness 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-centred approach is facilitated which leads to patient empowerment.’

The patient activation measure (PAM) is a 13-item questionnaire developed by Hibbard *et al* that focuses on ‘knowledge, skills and confidence that equip patients to become actively engaged in their own health’.^{11–13} 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 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 hospitalised.^{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 healthcare costs.¹⁸ Some studies looking at different interventions like online programmes 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 *et al* 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 3 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 characterised 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 generalised 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 were 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, mononeuropathy and polyneuropathy, vertigo, chronic ischaemic heart disease, angina pectoris, heart failure, peripheral artery disease, atherosclerosis, asthma, chronic obstructive pulmonary disease, 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 amount 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 3 months. A total of 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 Strengthening the Reporting of Observational Studies in Epidemiology guideline was used for reporting this study.

Data collection

Data were collected via standardised, 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. Standardised 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. Sociodemographic 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 healthcare, 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 1–4 (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 standardised 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 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 as follows: (1) preferences in treatment (2) treatment goals, (3) involvement in treatment, (4) patient training programme (5) support group (6) self-management plan, (7) medication plan, (8) review on medication, (9) information on medication and (10) 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 (3) were 'always' or 'usually' / 'rarely' / 'never'. All answers/items were dichotomised.

Statistical analysis

Descriptive statistics were calculated for all variables included in the analysis to examine means, SD, 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, a $p < 0.05$ 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 V.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 were excluded from the analysis.

Patient and public involvement

Patient representatives were involved in the rating and selection of the quality indicators, 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

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, 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 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)

Continued

Table 1 Continued

Sample characteristic	Sample description (n=346)
Level 3 (≥ 55.2 and ≤ 72.4)	94 (27.2)
Level 4 (≥ 72.5) (most activated)	210 (60.7)
Missing	3 (0.9)

CASMIN, Comparative Analysis of Social Mobility in Industrial Nations.

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 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 online 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 1283 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

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 value
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

* $p < 0.05$, significant domain.
PAM, patient activation measure.

activation scores. Nevertheless, only 3 out of 10 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 and Hibbard¹³ 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-centredness and patient activation and their link to positive health outcomes. The findings of patient's experiences with primary care could explain the connections.

Patients who 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 centred 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 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-centred 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 medication 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 for example, 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 programmes 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 heterogeneous 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 3 out of 10 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.

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

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by Ethics Committee of the Hamburg Medical School (PV5846) Ethics Committee of the Medical Faculty of the Heidelberg University (S-665/2018) Baden-Wuerttemberg regional medical board (B-F-2018-096). Participants gave informed consent to participate in the study before taking part.

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REFERENCES

- van den Bussche H, Koller D, Kolonko T, *et al*. Which chronic diseases and disease combinations are specific to multimorbidity in the elderly? results of a claims data based cross-sectional study in Germany. *BMC Public Health* 2011;11:101.
- France EF, Wyke S, Gunn JM, *et al*. Multimorbidity in primary care: a systematic review of prospective cohort studies. *Br J Gen Pract* 2012;62:e297-307.
- Gijzen R, Hoeymans N, Schellevis FG, *et al*. Causes and consequences of comorbidity: a review. *J Clin Epidemiol* 2001;54:661-74.
- Wallace E, Salisbury C, Guthrie B, *et al*. Managing patients with multimorbidity in primary care. *BMJ* 2015;350:h176.
- Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff* 2013;32:207-14.
- Wagner EH, Austin BT, Davis C, *et al*. Improving chronic illness care: translating evidence into action. *Health Aff* 2001;20:64-78.
- Poon BY, Shortell SM, Rodriguez HP. Patient activation as a pathway to shared decision-making for adults with diabetes or cardiovascular disease. *J Gen Intern Med* 2020;35:732-42.
- Kaboli PJ, Howren MB, Ishani A, *et al*. Efficacy of patient activation interventions with or without financial incentives to promote prescribing of thiazides and hypertension control: a randomized clinical trial. *JAMA Netw Open* 2018;1:e185017.
- Bodenheimer T, Wagner EH, Grumbach K. Improving primary care for patients with chronic illness: the chronic care model, part 2. *JAMA* 2002;288:1909-14.
- Castro EM, Van Regenmortel T, Vanhaecht K, *et al*. Patient empowerment, patient participation and patient-centeredness in hospital care: a concept analysis based on a literature review. *Patient Educ Couns* 2016;99:1923-39.
- Hibbard JH, Stockard J, Mahoney ER, *et al*. Development of the patient activation measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res* 2004;39:1005-26.
- Hibbard JH, Mahoney ER, Stockard J, *et al*. Development and testing of a short form of the patient activation measure. *Health Serv Res* 2005;40:1918-30.
- Greene J, Hibbard JH. Why does patient activation matter? an examination of the relationships between patient activation and health-related outcomes. *J Gen Intern Med* 2012;27:520-6.
- Kinney RL, Lemon SC, Person SD, *et al*. The association between patient activation and medication adherence, hospitalization, and emergency room utilization in patients with chronic illnesses: a systematic review. *Patient Educ Couns* 2015;98:545-52.
- Begun N, Donald M, Ozolins IZ, *et al*. Hospital admissions, emergency department utilisation and patient activation for self-management among people with diabetes. *Diabetes Res Clin Pract* 2011;93:260-7.
- Hendriks M, Rademakers J. Relationships between patient activation, disease-specific knowledge and health outcomes among people with diabetes; a survey study. *BMC Health Serv Res* 2014;14:393.
- Hibbard JH, Mahoney ER, Stock R, *et al*. Do increases in patient activation result in improved self-management behaviors? *Health Serv Res* 2007;42:1443-63.
- Hibbard JH, Greene J, Overton V. Patients with lower activation associated with higher costs; delivery systems should know their patients' 'scores'. *Health Aff* 2013;32:216-22.
- Frith G, Carver K, Curry S, *et al*. Changes in patient activation following cardiac rehabilitation using the Active™ digital healthcare platform during the COVID-19 pandemic: a cohort evaluation. *BMC Health Serv Res* 2021;21:1363.
- Regeer H, van Empelen P, Bilo HJG, *et al*. Change is possible: how increased patient activation is associated with favorable changes in well-being, self-management and health outcomes among people with type 2 diabetes mellitus: a prospective longitudinal study. *Patient Educ Couns* 2022;105:821-7.
- Hibbard JH, Greene J, Shi Y, *et al*. Taking the long view: how well do patient activation scores predict outcomes four years later? *Med Care Res Rev* 2015;72:324-37.
- Blakemore A, Hann M, Howells K, *et al*. Patient activation in older people with long-term conditions and multimorbidity: correlates and change in a cohort study in the United Kingdom. *BMC Health Serv Res* 2016;16:582.
- Gleason KT, Tanner EK, Boyd CM, *et al*. Factors associated with patient activation in an older adult population with functional difficulties. *Patient Educ Couns* 2016;99:1421-6.
- Overbeek A, Rietjens JAC, Jabbarian LJ, *et al*. Low patient activation levels in frail older adults: a cross-sectional study. *BMC Geriatr* 2018;18:7.
- Becker ER, Roblin DW. Translating primary care practice climate into patient activation: the role of patient trust in physician. *Med Care* 2008;46:795-805.
- Hibbard JH, Greene J, Becker ER, *et al*. Racial/Ethnic disparities and consumer activation in health. *Health Aff* 2008;27:1442-53.
- Alexander JA, Heard LR, Mittler JN, *et al*. Patient-Physician role relationships and patient activation among individuals with chronic illness. *Health Serv Res* 2012;47:1201-23.
- Alvarez C, Greene J, Hibbard J, *et al*. The role of primary care providers in patient activation and engagement in self-management: a cross-sectional analysis. *BMC Health Serv Res* 2016;16:85.
- Moumjid N, Gafni A, Brémond A, *et al*. Shared decision making in the medical encounter: are we all talking about the same thing? *Med Decis Making* 2007;27:539-46.
- Aung E, Donald M, Coll JR, *et al*. Association between patient activation and patient-assessed quality of care in type 2 diabetes: results of a longitudinal study. *Health Expect* 2016;19:356-66.
- Greene J, Hibbard JH, Alvarez C, *et al*. Supporting patient behavior change: approaches used by primary care clinicians whose patients have an increase in activation levels. *Ann Fam Med* 2016;14:148-54.
- Health Foundation. The Commonwealth fund's 2019 international health policy survey of primary care doctors in 11 countries.
- Ridic G, Gleason S, Ridic O. Comparisons of health care systems in the United States, Germany and Canada. *Mater Sociomed* 2012;24:112-20.
- Schulze J, Glassen K, Pohontsch NJ, *et al*. Measuring the quality of care for older adults with multimorbidity: results of the MULTiqual project. *Gerontologist* 2022. doi:10.1093/geront/gnac013. [Epub ahead of print: 28 Jan 2022].
- Pohontsch NJ, Schulze J, Hoefflich C, *et al*. Quality of care for people with multimorbidity: a focus group study with patients and their relatives. *BMJ Open* 2021;11:e047025.
- Schäfer I, Hansen H, Schön G, *et al*. The German MultiCare-study: Patterns of multimorbidity in primary health care - protocol of a prospective cohort study. *BMC Health Serv Res* 2009;9:145.
- Altiner A, Schäfer I, Mellert C, *et al*. Activating general practitioners dialogue with patients on their agenda (MultiCare agenda) study protocol for a cluster randomized controlled trial. *BMC Fam Pract* 2012;13:118.
- Hibbard J, Gilbert H. *Supporting people to manage their health: an introduction to patient activation*. London, 2014.

- 39 Mansfield ER, Helms BP. Detecting Multicollinearity. *The American Statistician* 1982;36:158–60.
- 40 Hibbard JH, Cunningham PJ. How engaged are consumers in their health and health care, and why does it matter? *Res Brief* 2008;1–9.
- 41 Rademakers J, Maindal HT, Steinsbekk A, *et al.* Patient activation in Europe: an international comparison of psychometric properties and patients' scores on the short form patient activation measure (PAM-13). *BMC Health Serv Res* 2016;16:570.
- 42 Brewster L, Tarrant C, Armstrong N. 'Patient activation' as an outcome measure for primary care? *Fam Pract* 2015;32:481–2.
- 43 Wensing M, Wetzels R, Hermsen J, *et al.* Do elderly patients feel more enabled if they had been actively involved in primary care consultations? *Patient Educ Couns* 2007;68:265–9.
- 44 Menichetti J, Graffigna G, Steinsbekk A. What are the contents of patient engagement interventions for older adults? A systematic review of randomized controlled trials. *Patient Educ Couns* 2018;101:995–1005.
- 45 Magadi W, Lightfoot CJ, Memory KE, *et al.* Patient activation and its association with symptom burden and quality of life across the spectrum of chronic kidney disease stages in England. *BMC Nephrol* 2022;23:45.
- 46 Deutsche Gesellschaft für Allgemeinmedizin und Familienmedizin. *Multimorbidität S3-Leitlinie* 2017.
- 47 Fowles JB, Terry P, Xi M, *et al.* Measuring self-management of patients' and employees' health: further validation of the patient activation measure (PAM) based on its relation to employee characteristics. *Patient Educ Couns* 2009;77:116–22.
- 48 Lubetkin EI, Lu W-H, Gold MR. Levels and correlates of patient activation in health center settings: building strategies for improving health outcomes. *J Health Care Poor Underserved* 2010;21:796–808.