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Patients' perspectives on involvement in general practice: A thematic analysis of free-text comments

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Abstract

Background: General practice (GP) plays a core role in managing the clinical pathways of patients with chronic diseases. Despite well-established knowledge of the benefits of involvement and personalized care, involvement in GP appears to be challenged. This study aimed to explore patient involvement in GP from the patients' perspectives.

Method: The study involved a questionnaire survey investigating patient involvement in GP from the patients' perspectives. The validated questionnaire includes an open-ended question encouraging responders to provide additional comments regarding their involvement in GP. The results from these comments are presented in this paper. A thematic analysis was applied.

Results: Of the 468 responses, 139 included additional comments to the free-text question. Through our analysis, six analytic themes were generated—*To be seen, met or heard*, *To feel safe or not*, *To be involved or dictated to*, *Accessibility*, *COVID-19*, and *For the resourceful*—across 116 codings and 25 descriptive themes. The themes' interwovenness underscores the complexity of both involvement and how it is to live with a chronic disease. Our analysis indicates that involvement in GP is for the resourceful.

Conclusion: The six themes describing involvement in GP from the perspectives of patients with T2DM and/or COPD were deeply intertwined. Involvement is dependent on being seen, met and heard, all of which contribute to the patients' sense of feeling safe (or not). These aspects are dependent on accessibility to a general practitioner; thus, COVID-19 was a barrier during the data-collection period. Furthermore, it appeared that being resourceful not only contributed to a sense of being involved in GP but was perhaps even a prerequisite for being involved.

KEYWORDS

chronic disease, COVID-19, general practice, involvement, patient involvement, patient perspectives

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1 | BACKGROUND

General practice (GP) plays a key role in managing the clinical pathways of patients with chronic diseases.¹ For general practitioners (GPs), this role is primarily regarded as burdensome and challenging.² However, being diagnosed with a chronic disease also includes multiple challenges for the patients, including the struggle to manage everyday life with a chronic disease. Examples of chronic diseases managed mainly by GPs^{3–5} are chronic obstructive pulmonary disease (COPD) and type 2 diabetes (T2DM), both of which are incurable and represent major health problems.⁶ Patients with COPD or T2DM tend to have complex clinical pathways characterized by multiple contacts across the healthcare system⁷; thus, they need to cope with and manage their disease. Moreover, patients with chronic diseases also struggle to collaborate with their GPs regarding different understandings of the disease, lack of sufficient and effective communication, and differences in prioritization and rating of the disease, in addition to more personal challenges such as obliviousness, repression and avoidance.⁸

Despite the increased focus on patient involvement in healthcare practice and well-established knowledge of the benefits of involvement and personalized care, including improved health outcomes^{9,10} increased satisfaction,¹¹ enhanced quality of life, improved mental health^{12,13} and increased compliance¹⁴—let alone reduced costs for healthcare^{10,15–17}—it appears that involvement in GP is also challenged.^{18,19} However, patient involvement is increasingly recognized as beneficial to chronic disease management,¹⁰ and involving patients in treatment and healthcare delivery further benefits healthcare professionals by enhancing their understanding of patients' health problems and enabling them to deliver individualized healthcare.²⁰ Knowledge regarding how patients with COPD and T2DM experience involvement in their treatment is important so that the best possible care can be provided. Thus, this study aimed to explore patient involvement in GP from the patients' perspectives.

2 | METHODS

2.1 | Study design, setting, participants and data collection

The present explorative study comprised a questionnaire survey investigating patient involvement in GP from the patients' perspectives (results are reported elsewhere). The survey was designed as a descriptive cohort study including patients diagnosed with either T2DM or COPD. Data were collected using the validated Danish version of the 9-item Shared Decision-Making Questionnaire (SDM-Q-9).²¹

Patients with either T2DM or COPD (or both) aged 18 years or older were included. In March–April 2021, the survey was distributed through the Danish Diabetes Association and Danish Lung Association. Both organizations provided contact to their members through their local branches. An e-mailed link gave access to the questionnaire.

At the end of the questionnaire, a single open-ended question encourages responders to add further comments regarding their involvement in GP. Data from this open-ended question are presented in this study.

Because this research was part of a larger descriptive study, we did not apply reflections on number of participants (e.g., data saturation), interviewer characteristics, or relationships between participants and researcher, although we do acknowledge the importance of these areas. Our sample is considered to be of convenience form.

2.2 | Analysis and reporting

To meet the fact that our data—as a consequence of the method—appear relatively brief and concise, we chose to apply a thematic analysis as described by Thomas because this approach is considered robust even for less rich and nuanced qualitative data.²² The strategy includes three steps: coding text, developing descriptive themes and generating analytical themes (*ibid.*). As an additional precaution, the data were extracted and analysed by three authors (B. N., S. B. T. and M. M.).

The analytical strategy began with coding and extraction of findings (Step 1). Data extraction was approached inductively, and the extracted data were then grouped according to similarity in meaning as judged by all authors. Through this process, the descriptive themes emerged (Step 2), and in Step 3, we generated analytic themes. We looked for relationships between the descriptive and defined analytic themes, gathering the descriptive themes into fewer major groups (themes). The final themes reflect a consensus agreement among all the authors.

In reporting the findings, we primarily present the descriptive themes, including the number of codings and analytic themes constructing the respective themes. However, when our data include illustrative quotations to support the themes, these quotations will also be presented. Because our informants remain anonymous due to the data-collection method, the quotations will only be identified by diagnosis (if possible) and not by participant number, age or sex.

2.3 | Ethical considerations

The survey was approved by the Research Ethics Committee of the University of Southern Denmark (id 21/8757), in agreement with both research ethics and General Data Protection Regulation (GDPR) legislation.²³ The questionnaire was preceded by information about the purpose of our study, contact information, anonymity, confidentiality, and the responders' right to withdraw from the study at any time. An informed consent box was ticked initially by all responders, thus accepting that data could be used for research. According to Danish legislation, no further approval was necessary.

3 | RESULTS

Of the 468 responders of the questionnaire, 139 included additional comments to the free-text question. The respondents (from here: informants) who added comments had a mean age of 69 years, 76 (55%) were women, 63 (45%) men; 85 (61%) stated that they had T2DM or 56 (40%) COPD, whereas 12 noted that they had both.

Some informants commented on the questionnaire's wording (relevance and lack of a 'Not relevant' answer option), a few simply answered 'No' or 'None', and yet others briefly explained why they considered it irrelevant to answer the question. However, several respondents added both short, informative and longer, more detailed comments suitable for the thematic analysis.

In Step 1, a total of 116 codings were recorded, resulting in 25 descriptive themes (Step 2). In Step 3, six analytic themes were generated: *To be seen, met or heard*, *To feel safe or not*, *To be involved or dictated to*, *Accessibility*, *COVID-19*, and *For the resourceful*. The analytic themes included descriptive themes of both a positive and negative nature (e.g., Being involved—Don't get choices), except for the theme COVID-19, which only reflected negative codes and descriptive themes. Although intertwined, the analytic themes are presented individually to ensure that the nuances provided by the informants are included. In Table 1, the coding tree is presented.

3.1 | To be seen, met or heard

Intuitively, to be seen, met and heard are prerequisites for being involved. This theme was one of the most prominent (32 codes), represented by both positive and negative sides. A few informants wrote clearly and unambiguously: 'I always feel welcome', or 'My GP sees me'. However, a significant number of informants expressed that they were not heard or not met, that they felt superficially treated, and the general practitioner (GP) only did what was absolutely necessary: 'They act textbook wise'. The informants commented that they had been challenged by their chronic disease but had a sense that the GP '... does not think it is that bad' or is not interested at all. Of those stating that their GP was not interested, seven were diagnosed with COPD and one with DM. Informants from both groups noted that their GP did not listen to them and did not understand how it is to live with a chronic disease.

3.2 | Accessibility

Accessibility is also considered a prerequisite for involvement. This theme was represented by 13 codes and two descriptive themes—*A challenge to get access to the GP* and *The nurse do not know that much*—and, thus, primarily visible as negative experiences. Some informants stated that their regular control visits were mainly managed by a nurse and that they only obtained access to the GP once a year, as in: 'I did only speak to a nurse', or 'I have only had written communication with my doctor, which has been one-way

TABLE 1 Coding tree (descriptive themes and analytic themes).

Descriptive themes	Analytic themes
I always feel welcome	To be seen and heard
I am seen [by the GP]	
I do not feel heard	
My wishes are not met	
The GP is not interested in COPD (n = 7)/Diabetes (n = 1)	
The GP does not listen to the patient's knowledge	
Superficial	
The GP does not think it is that bad	
It is quite a burden to live with a chronic disease	
The GP does not understand the problems related to diabetes	
They act textbook wise	
It is difficult to get access to a GP	Accessibility
The nurse does not know that much	
Challenges due to COVID-19	COVID-19
I feel that I am involved	To be involved or dictated to
I prefer close collaboration	
The treatment is dictated	
I don't get choices	
I feel safe	To feel safe or unsafe
I feel satisfied	
The GP knows too little about COPD/ diabetes	
I wish for specialist treatment	
I feel unsafe	
I feel that I am involved	To be involved or dictated to
I prefer close collaboration	
The treatment is dictated	
I don't get choices	
You have to be resourceful	For the resourceful
You have to look for information yourself	
You are left alone	
I don't receive much help	

Abbreviations: COPD, chronic obstructive pulmonary disease; GP, general practice.

communication'. Only a few of these comments were directly negative, as in: 'Haven't seen a doctor for years—my treatment has been managed by a nurse, and they haven't all been that good to handle diabetes problems', whereas most comments related to this



theme were rather a laconic realization that they had not seen a doctor but a nurse.

3.3 | COVID-19

Closely related to accessibility was the analytic theme *COVID-19*, representing 10 codes and a similar descriptive theme. Even though some informants voiced some indignation and a sense of being neglected and overseen not having seen a doctor for some time, other informants expressed acceptance and explained this feeling with COVID-19. They had either been offered a telephone consultation instead of a face-to-face consultation or had their consultation postponed due to COVID-19. Why the informants mentioned this when asked about their involvement remains unclear. However, some informants explained that these telephone consultations tended to be short and primarily focused on information about test results, whereas other informants explained the lack of involvement by the presence of COVID-19 prohibiting face-to-face consultations.

3.4 | To be involved or dictated to

The core theme within this analysis was *To be involved or dictated to*. This theme included 37 codes and four descriptive themes: *To be involved*, *Close collaboration*, *Treatment is dictated*, and *Get no choices*—and was, thus, also represented by both positive and negative sides. Some informants mentioned that they had expressed a wish to either see a doctor (*not* a nurse), have their disease managed by a specialist nurse (*not* a GP), or have their disease managed by a specialist hospital (*not* a GP) without being heard. Another group of informants stated that their treatment, medication, or tests were not discussed, and alternatives were not presented; they stated that these aspects were dictated. One informant stated, 'I was not asked....I was told what I was not allowed to do and which medication I had to take', and another informant described in more detail:

Ten years ago, I was diagnosed with Diabetes Type 2. I was offered Metformin[®] but said no. I changed my diet and exercised. I still do. This caused my blood sugar to decrease. Ten years have passed, and particularly exercise has kept my blood sugar down. But the treatment option was drugs and not exercise. So, I have actively opted out of the GP's options and chosen an active lifestyle.

However, there were also some statements indicating a good and informed dialogue concerning lifestyle changes and choice of medication, leaving a sense of being involved: 'My doctor appreciates that I am involved in both trajectory and medication; I am very lucky and satisfied....'

It appeared that the informants equated *being asked* and *involvement*; being informed tended to result in a sense of being

dictated to, whereas information followed by dialogue and a question of what the patient preferred seemed to result in a sense of being involved. This process is described rather precisely by one informant: 'I was informed but not met'.

3.5 | To feel safe or not

This theme was reflected by 32 codes and the five descriptive themes: *To feel safe*, *to be satisfied*, *The GP knows too little about COPD/diabetes*, *A wish for specialist treatment*, and *To feel unsafe*. On the positive side of this theme, several informants simply stated: 'I am satisfied', 'I feel safe' or 'I am taken seriously'. However, most comments in this theme evolved around the informants' sense that the GPs lacked knowledge of their disease—this applied for both patients with T2DM and COPD. The informants stated that they were superficially instructed, that they had to seek information themselves, and that they were worried about misinformation due to these aspects:

I have only received very superficial instruction regarding diet and exercise. I had to seek the information through the diabetes association. Of course, I have also looked at social media, and if you only get your information from there and not from more reliable sources (which I, after all, think the diabetes association is), then you risk being thoroughly misinformed, particularly regarding diet. Many strange diets that are harmless at best have been well described.

This being-left-on-one's-own situation left some informants with a sense that things are handled randomly and of feeling unsafe. Several informants mentioned what they experience as the GP's lack of knowledge about the diagnosis and about recent research. On the other hand, other informants stated that they experienced a high sense of safety, adequate follow-up, and a good dialogue.

Although this theme emerged unambiguously, it appeared to be closely related to the former themes, particularly *To be seen*, *met or heard* and *To be involved or dictated to* but also both *Accessibility* and *COVID-19* because the sense of feeling safe (or not) depended on whether they were seen, met, heard, involved, informed, and/or had access to their GP when required.

3.6 | For the resourceful

The final analytic theme—*For the resourceful*—included 14 codes and four descriptive themes: *You have to be resourceful*, *You have to look for information yourself*, *You are left alone*, and *I don't receive much help*. Despite some informants explicitly writing: *You have to be resourceful*, this theme can be considered the essence—or rather the consequence of—the previous themes. When having to

seek information oneself, accept online or postponed consultations, or change into a healthier lifestyle on one's own, being resourceful will consequently be advantageous. Within this theme, the informants stated: 'There is no follow-up; I have initiated control by an ophthalmologist—this is my own responsibility'. Initiation of either specialist assessment or follow-up by the GP is mentioned by more informants: 'I asked for additional control of blood sugar' and 'There was no plan—I asked for it myself'. The detailed citation presented in the former theme (*To feel safe or not*) is also an illustrative example of a resourceful patient; the informant comments upon the risk of being misinformed (i.e., lack of safety) but recognizes superficial information, seeking information, and recognizing the risk of misinformation would generally be a challenge for less resourceful patients. Hence, although the quote adopted as a label for this theme—*You have to be resourceful*—was most likely meant to explain how this informant experiences being a patient with a chronic disease managed in GP, our analysis might indicate that involvement is also for the resourceful.

4 | DISCUSSION AND CONCLUSION

4.1 | Discussion

Across 116 codings and 25 descriptive themes, six analytic themes were generated: *To be seen, met or heard*, *To feel safe or not*, *To be involved or dictated to*, *Accessibility*, *COVID-19*, and *For the resourceful*. The themes' interwovenness underscores the complexity of both involvement and how it is to live with a chronic disease, and we believe that each theme contributes valuable patient involvement knowledge in GP as experienced by patients with T2DM or COPD.

Despite the numerous positive expressions obtained from the free-text question encouraging the survey-responders to add comments on their involvement in GP, it is striking to see how several of the informants are challenged by living with a chronic disease, by obtaining access to a GP or specialist treatment, and by being involved in treatment decisions. Thus, our results corroborate those of similar studies finding that collaboration between patients and GPs is challenged by, for example, issues with communication, differences in the understanding of a disease, and prioritization and rating of diseases.⁸ Furthermore, the GPs are challenged in their management of chronic disease pathways because they appear to struggle to balance between delivering evidence-based care and the patients' right to be involved in decision-making.¹⁸

The theme—*For the resourceful*—our indication that this might apply not only for being a patient with a chronic disease but for the involvement itself is substantially supported by other researchers. A recent review has identified that representativity is a general issue in studies investigating involvement—not only regarding those included in the studies but also with respect to participation in patient and public involvement (PPI). Hence, PPI tends to involve the most socioeconomically advantaged patients, and the challenges of

reaching and engaging less advantaged and even patients with a low level of health literacy are overarching.²⁴

In our study, COVID-19 was also a factor to consider. For the informants, the pandemic was a condition that compromised their communication with their GP either because their consultation was postponed or replaced with an online consultation. COVID-19 also appeared as a kind of frame the informants used to explain a lack of follow-up and insufficient information, dialogue, and involvement, corroborating novel research documenting an extensive deployment of both virtual and telephone consultations during this pandemic but also that virtual consultations ideally should be more patient-centred.²⁵ Furthermore, particularly for cases that require managing more complex or chronic conditions, virtual consultations pose challenges.²⁵ To underscore the vulnerability of the less advantaged or less resourceful, COVID-19 contributes to this skewness. Patients with chronic conditions were deprioritized during the pandemic compared to patients with either infectious or acute illnesses; the less advantaged will consequently be more challenged when self-managing their chronic conditions and risk substantial impact on their psychological and socioeconomic well-being.²⁶

4.2 | Limitations

We consider the data collection method a limitation of this study because our approach left no possibilities for explaining our intention or to clarify what the informants may have had in mind when answering. This issue might have compromised the level of details and richness of our data. On the other hand, the range of the survey that the free-text question was appended extended the reach of our study; we obtained numerous comments from responders that would have been impossible for us to receive in a typical qualitative design. Furthermore, we reached data saturation beyond ambiguity and, thus, a high level of credibility. The lack of interviewer–informant interactions that traditionally compromises an explorative design could also be claimed to be a positive feature in our study regarding its dependability because each informant was asked the same question using a uniform procedure. Acknowledging these possible threats towards the quality of our data collection, we determined that all authors should engage in the analysis with the primary aim to consider the data as they appeared. Thus, we believe that our study is sound and rigorous despite its methodological shortcomings, and we suggest that the results are applicable in practice.

5 | CONCLUSION

The six themes describing involvement in GP from the perspectives of patients with T2DM and/or COPD were deeply intertwined. Involvement is dependent on being seen, met and heard, all of which again contribute to the patient's sense of feeling safe (or not). These aspects were found to be dependent on accessibility to a GP; thus, COVID-19 was a barrier during the data-collection period.



Furthermore, it appeared that being resourceful not only contributed to a sense of being involved in GP but perhaps even a prerequisite for being involved.

AUTHOR CONTRIBUTIONS

Designing the study: Birgitte Nørgaard, Signe Beck Titlestad, Michael Marcussen. *Data collection:* Birgitte Nørgaard, Signe Beck Titlestad, Michael Marcussen. *Data analysis:* Birgitte Nørgaard, Signe Beck Titlestad, Michael Marcussen. *Manuscript:* Birgitte Nørgaard, Signe Beck Titlestad, Michael Marcussen. All authors have contributed substantially to this paper.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data collected and analysed during the current study are not publicly available due to Danish legislation. However, the corresponding author will be happy to answer any questions about these data.

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