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BMJ Open Quality Exploring power shifts as an enabler for a strengthened patient role in quality improvements: a Swedish survey study

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ABSTRACT

Objectives This study examined the relationship between professionals' perceptions of a strengthened role for the patient and of patient involvement in quality improvement (QI) and whether professionals' experiences in improvement science were a moderator on such a relationship.

Design From a predominantly close-ended, 44-item questionnaire, 4 questions specifically concerning professionals' perception on patient involvement in QI were analysed.

Setting Three Swedish regions.

Participants 155 healthcare professionals who had previously participated in courses in improvement science.

Results The covariate patient involvement was significantly related to a perceived strengthened patient role. There was also a significant interaction effect between degree of patient involvement and professionals' experience in the area of improvement science on a strengthened patient role. The result shows that there is a relationship between the perceived level of patient involvement in improvements and professionals' perceptions of a strengthened patient role. In this study, the covariate, perceived patient involvement, was significantly related to experiences of more equal relationships between patients and healthcare professionals. There was also a significant interaction effect between the degree of patient involvement and professionals' experience in the area of improvement science, for a more equal relationship between patients and healthcare professionals.

Conclusion Increased patient involvement in QI is a means of strengthening the patient role and supporting a more equal relation between patients and healthcare professionals. Furthermore, empirical evidence shows that the healthcare professionals' experiences in the area of improvement science support a strengthened patient role and a more equal power relationship, but for this to happen, the mindset of professionals is key. Future research is needed to capture and investigate the experiences from patients and relatives about being involved in QI in healthcare, and to study the effects on quality in care processes.

INTRODUCTION

This paper presents a perspective on healthcare quality improvement (QI) by addressing the change in power relationships that arises

from the increased patient involvement in a healthcare system that traditionally has been regarded as profession-centric. The paper argues that QI in healthcare is enhanced by more active involvement of patients, which in turn acts as a mechanism for mobilising a move from profession-centric healthcare towards a more power-balanced situation.

Traditionally, healthcare has been regarded as profession-centric, characterised by a multiplicity of professional logics and specialisations.^{1 2} In a knowledge-intense setting, a certain type of expertise or knowledge interest will prevail over others.³ As result of an imbalance where healthcare professionals will prevail over the patients in certain situations, patients may perceive communication and interaction with healthcare professionals as being one-sided or insufficient.⁴⁻⁶ Patients often complain that they are not being listened to or taken seriously.⁷⁻⁹ Dissatisfaction concerning this is likely to be under-reported by patients.¹⁰ However, the voice of patients is important not only in identifying deficiencies but also as a component of QI in healthcare,⁷ which is the focus of the present paper.

It is commonly argued that patient involvement contributes to more effective and efficient healthcare delivery that, in turn, leads to lower costs, better medical results and increased patient satisfaction.^{3 5 11 12} A frequent critique, however, is that the effects of patient involvement are still not fully established, and that patient involvement is a time-consuming and resource-consuming endeavour.¹³⁻¹⁵ Besides the instrumental logic based on economic rationality for involving patients in QI, democratic arguments based on communicative-oriented and consensus-oriented rationality may also be used, including an emphasis on fair participation in decision-making and representative inclusion of marginalised voices.¹⁶⁻¹⁸ Irrespective of such arguments, the involvement



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of patients is of particular concern in the Swedish context of the present paper. Swedish patients with complex care needs are reported to be less satisfied with their interactions with healthcare professionals than patients in other Western countries¹⁹; moreover, it has been shown that a patient's perspective and patient involvement are often lacking in Swedish healthcare.^{20 21}

Traditionally, QI in healthcare has been the domain of the professionals.^{22 23} By this stress, healthcare service improvement entails an inside-out perspective, driven by strong professional groups, where patients are not sufficiently seen as active partners in the development of healthcare services.^{12 24} However, during recent decades, increased emphasis has been placed on the role of the patient in the delivery of healthcare,²⁵ as well as healthcare organisation and management.^{26 27} The contemporary patient role also includes taking part in improvements not only in one's own care but also in the care of other patients.^{28–31}

Improving contemporary healthcare is not possible without professionals and other stakeholders realising the benefit and reasons to include the voice of patients in QI.^{3 32 33} In fact, by involving stakeholders even in research projects aiming for change, reach, rigour and relevance can be improved.³⁴ Recent studies also show that involving patients in QI leads to more radical suggestions for improvement and innovations.³⁵ As suggested in Greenhalgh *et al*'s³⁶ review on diffusion of innovations in healthcare, there is a broad range of determinants influencing successful spread of innovations or innovative ways of working. These range from influence from the outer context and its sociopolitical climate to the user system, including system readiness for innovation, adopters, assimilation and implementation process. Centring on patient involvement, Luxford *et al* [²³, p513] argue that the most common barrier to increased patient focus 'the mindset of employees from a 'provider-focus' to a 'patient-focus'. Thus, in this paper we focus on the relation between staff and patients in the user system, although acknowledging that there are other critical determinants also influencing changed practices related to patient involvement. The purpose of this paper was to investigate healthcare professionals' perspectives on patient involvement in QI in order to explore shifts in power as an enabling mechanism for a strengthened patient role. Furthermore, it is investigated whether healthcare professionals' earlier experience of working in projects with patient involvement has a moderating role on the perceived effect of patient involvement on the patient role.

LITERATURE AND CONCEPTUAL FRAMEWORK

As the traditional role-casting between healthcare professional and patient develops, clearly the notion of the patient as a passive receiver of healthcare (information and treatment) and dependence on professionals' expertise³⁷ is ill fit. As healthcare is not 'produced' to waiting patients, patients are regarded as actors interacting

with healthcare professionals as equal actors.³⁸ Not only delivery but also QI take place in the interaction between these two actors³⁹ and thus alter the power relation between them.

Power relation between healthcare professionals and patients

Power can be seen as a resource that is possessed by some and lacked by others and that can be won or lost,⁴⁰ or something that healthcare professionals can 'give' in order to empower patients.⁴¹ Power may also be conceived as shaping the agenda and thereby dictating who is allowed to participate, or as transforming the powerless so that they (often unconsciously) act in accordance with the desires of the powerful.^{40 42} A radically different notion of power is suggested by Foucault,^{43 44} wherein power should be understood as diffuse rather than concentrated in and possessed by individuals. Here, power acts in more subtle ways through norms⁴¹ within discourses that define what can be said and done (and not). Within a discourse, power and knowledge cannot be separated⁴⁵ because power both derives from and makes use of knowledge, and in so doing reproduces what is considered valid knowledge within the boundaries of the discourse.⁴⁶

As knowledge and power are intertwined in a Foucauldian conception of power, access to knowledge and participation in knowledge production is essential for patients as well as professionals to extend the boundaries of what is seen as possible to do—thus, the arguments to enhance participative approaches of knowledge production are to address asymmetric relationships to be 'transformed into subject/subject rather than subject/object' [⁴⁷, p5]. Healthcare professionals sometimes see the patient as an objectified patient, not a person with the potential to be a partner in QI. Hence, the reconceptualisation of the patient role becoming a codesigner⁴⁸ of care in improvement may be of value in supporting person-centred care.⁴⁹ Furthermore, involvement in design and improvement of care processes is argued to support the patient in becoming a more empowered partner to healthcare professionals.⁵⁰ However, research on involvement in QI and the actual influence on patient empowerment and the power relations between patients and healthcare professionals is scarce.^{51 52}

Conceiving power as a resource that is possessed not solely by individuals recognises that inequities between professionals and patients should be understood as embedded in a healthcare discourse that shapes the possibilities and restrictions of both parties.⁴⁰ This study views power as 'the ability to influence the decision variables' [53, p177] of another actor. The relative power position of the two actors is determined by the resources and knowledge controlled by each party.^{53 54} For healthcare providers, the study builds on Batalden and Stoltz's⁵⁵ view on the necessity of both professional and improvement knowledge. Based on this view and derived from the field of purchasing,^{53 56} four (I–IV) categories of power

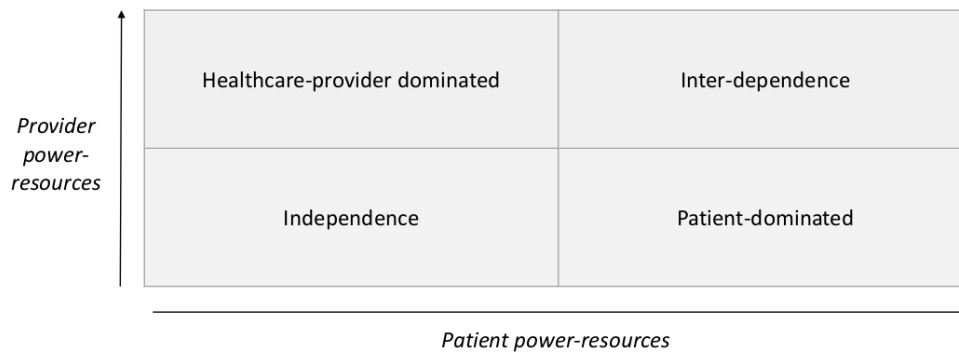


Figure 1 Power balance and categories of power positions between healthcare professionals and patients, inspired by Rehme *et al* and Cox.^{53 56}

positions between healthcare professionals and patients can be identified (see figure 1).

From a single actor's perspective, a power imbalance can be seen as a favourable position. On the one hand, the literature on relationship management prescribes that the power balance between two actors should be managed in a way that gives the buyer a range of options with respect to one or more suppliers,⁵⁶ that is, in this case, a (1) patient-dominated position; on the other hand, the literature on healthcare services reveals the (2) dominance of professionals over patients^{22 23}; a third stream of research argues for quality achievement as the result of a (3) joint development^{28 57}; a higher level of mutual dependence—interdependence—arises when the two actors aspire to the same goals and achieving greater performance is conditional to each other's actions⁵⁸; finally, (4) independence, regarded here as a rare case in healthcare, refers to a situation where the individual patient is of very limited importance for the professional, and where any effort towards QI would be made in terms of the patient finding another healthcare provider. This presumes that an abundance of options available to the patient and that services are standardised. The categorisation helps also to understand possible changes in power positions as a result of changes in the underlying determinants.^{53 59}

Conceptual framework

Figure 2 suggests that a strengthened patient role has the potential to open new ways of working with QI based on patients' unique experiences. A higher degree of patient involvement is expected to lead to a strengthened patient role.

According to the left-hand side of the conceptual framework in figure 2, professionals need to possess knowledge in improvement science,⁵⁵ presuming that they could carry out their own QI projects as well as act as facilitators of the QI projects of others. In fact, training healthcare professionals in improvement science has been shown to foster long-term improvement capability on an individual as well as organisational level.⁶⁰ On the right-hand side, patient involvement is argued to support a strengthened patient role, thereby promoting a changed power structure. Investigating QI from such a perspective, the study builds on the literature on buyer-supplier relationships.^{53 58} In this paper, a strengthened patient role refers to a transition towards a more equal power relation between healthcare professionals and patients. Experience from working with improvement science (in addition to professional medical knowledge) is seen as a moderator on the effect of patient involvement on a strengthened patient role. Based on figure 1, two research questions were formulated:

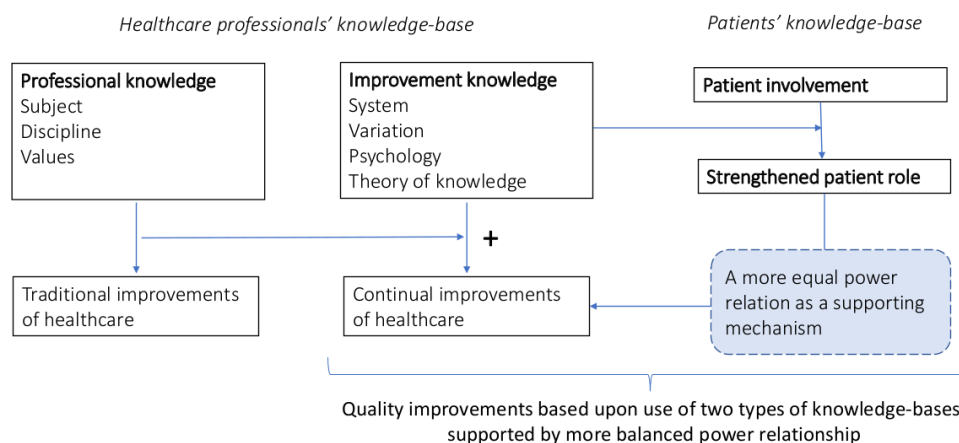


Figure 2 Combining knowledge bases of healthcare professionals⁵⁵ and patients to support quality improvements.

- Is there a relationship between patient involvement in QI and a perceived strengthened role for the patient?
- Are professionals' experiences in the area of improvement science a moderator on the relationship between patient involvement and a perceived strengthened patient role?

METHODS

Design and data collection

A questionnaire including a cover letter and 44 questions was developed, partly based on three validated questionnaires.^{50 61 62} Most questions were closed-ended and included information of the respondent's background, experiences of facilitating improvement projects, organisation and context, results from QI projects, and individual experiences of patient involvement. A pilot questionnaire was tested by a focus group including five healthcare professionals from different healthcare organisations, all of whom had taken courses in improvement science. The test led to improvements of the questionnaire in, for instance, clarification of questions.

The survey was conducted using a web-based survey tool (fluidsurveys.com) The sample included healthcare professionals currently, or previously, working with QI projects. The original sample was based on a list of 472 participants in courses in improvement science in three Swedish regions. We further used snowball sampling, where respondents in the original sample provided e-mail addresses for 19 additional respondents. In all, 491 questionnaires were administered to respondents, each of whom got two reminders by email. A total number of 155 respondents completed the entire questionnaire, yielding a response rate of 32%. In addition, since several respondents (n=32) no longer worked in healthcare or were on extended sick leave, the adjusted response rate was 34%.

Measurement instrument

The present study draws on four questions out of the 44 in the survey presented previously. First, the dependent variable (strengthened patient role) was measured on the level of agreement to these statements:

- 'The power relationship between health professionals and patient/relatives was changed and became more equal'.
- 'The patients'/relatives' position was clarified and strengthened'.

A 5-point Likert-type scale, with choices ranging from 'not at all' to 'to a very high degree' was provided. Second, in exploring if a higher degree of patient involvement in QI leads to a strengthened patient role, the independent variable (degree of patient involvement) was measured through the following questions:

- 'To what extent have patients and/or relatives been involved in implementing improvements along with the healthcare professionals?' in a 5-point scale from 'not at all' to 'to a very high degree'. Third, the moderator variable about experiences from the area

of improvement science was measured through the question:

- 'Have you previously been a leader or facilitator for improvements which patients and/or relatives have been involved in?'⁴⁹

Answers were given as either 'yes' or 'no'.

Data analysis

SPSS V.22 was used for analysing the data. Studying the impact of a strengthened patient role, we used Pearson's correlation coefficient. To explore the relationship between patient involvement, professionals' experience in improvement science and the patient role, a moderated regression model using the generalised linear model was employed. Two different regression models were generated, each with a different dependent variable (ie, strengthened patient role and changed power relationship between patients and healthcare professionals). Both models were built on two terms: the main effect for the degree of patient involvement and an interaction effect between the covariate patient involvement and the fixed factor professionals' experience and knowledge.

RESULTS

Of the 155 respondents, the gender distribution was 75.5% female and 23.3% male, and 1.3% of the respondents did not report gender. Regarding professions, 45.8% of the respondents were nurses; 12.3% were physicians; and the remaining group included a variety of other professions, such as physiotherapists, occupational therapists and psychologists. That more women than men responded and that most of the respondents were nurses reflect the prevailing circumstances in Swedish healthcare. Further, a majority of the respondents (63.9%) reported previous experiences in facilitating QI projects with patient involvement. One respondent reported on a project involving patients conducted already back in 1979, but most of the mentioned projects were conducted after 2010. For the two dependent variables (measured on a 5-point Likert-type scale, 1='not at all' to 5='to a very high degree'), the overall mean score was 3.74 (n=136, SD 1.32) on 'The patients'/relatives' position was clarified and strengthened', and 3.17 (n=136, SD 1.158) for 'The power relationship between health professionals and patient/relatives was changed and became more equal'.

Our data indicate significant correlations between a strengthened patient role and a more equal power relationship between patient and healthcare professionals (see [table 1](#)), such as being able to address new patient needs.

Departing from the results in [table 1](#) that strengthened patient role and a more equal power relationship are significantly correlated, it is of interest to move further in understanding how patient involvement in QI contributes to strengthening the patients' role in healthcare. In this study, the covariate patient involvement, that is, our

Table 1 Pearson correlation between strengthened patient role and equal power relations

| | | Strengthened patient role | Equal power relations |
|---------------------------|---------------------------|---------------------------|-----------------------|
| Strengthened patient role | Pearson correlation | 1 | 0.748* |
| | Significance (two-tailed) | | p<0.001 |
| | N | 136 | 135 |
| Equal power relations | Pearson correlation | 0.748* | 1 |
| | Significance (two-tailed) | p<0.001 | |
| | N | 135 | 136 |

*Correlation is significant at the 0.01 level (two-tailed).

continuous predictor variable, was significantly related to a strengthened patient role ($F(1.119)=20.2$, $p=0.000$). There was also a significant interaction effect between the degree of patient involvement and professionals' experience in the area of improvement science on a strengthened patient role ($F(1.119)=4.15$, $p=0.044$). The predicted model has $r^2=0.194$ (see [table 2](#)).

The result shows that there is a relationship between the level of patient involvement in QI and professionals' experiences of a strengthened patient role. In this study, the covariate, patient involvement, was significantly related to a more equal relationship between patients and healthcare professionals ($F(1.120)=21.94$, $p=0.000$). There was also a significant interaction effect between the degree of patient involvement and professionals' experience in the area of improvement science, on a more equal power relationship between patients and healthcare professionals ($F(1.120)=3.81$, $p=0.053$). The predicted model has $r^2=0.201$ (see [table 3](#)).

In summary, the regression analyses in [tables 2 and 3](#) show that working with degree of patient involvement does impact both the patient's role and power relations between professionals and patients. Moreover, experiences in improvement science act as a moderating effect, implying that such knowledge enhances the influence of patient involvement on a strengthened role.

DISCUSSION

The importance of strengthening the patient role has been pointed out in previous research, as, for example, in the area of person-centred care.⁴⁹ Building on the notion of a power balance between the professionals and patients, three key implications are suggested. First, patient involvement in QI appears to enhance the patient role and hence strengthens the patient's power position. Second, empirical evidence from this study supports the criticality of healthcare professionals' knowledge and experience of improvement science. Third, the paper aids the understanding of a movement of power balance towards interdependence between professionals and patients.

First, the results on enhanced patient role are in line with the view on power as including but not being bound to individuals⁴² but rather to discourses,^{43 44} '[p]ower in this way may not be a zero-sum relationship' [40, p176]; that is, increasing the patient's role does not mean that power for professionals decreases, rather it is a case of an interdependent power relation. This also means that in organising and managing healthcare, we need to recognise that, within the discourse, power shapes certain types of roles and impacts relationships between actors. Similar to the findings of Visser *et al*,⁴¹ in which online communities for patients were guided by norms of what could be discussed and what could not, patients' roles are also restricted by what is allowed within the healthcare discourse. When patients are invited to collaborate with healthcare professionals in improvement projects, their

Table 2 Regression results for strengthened patient role

| Source | Type III sum of squares | df | Mean square | F | Significance |
|--|-------------------------|-----|-------------|---------|--------------|
| Corrected model | 25.255* | 2 | 12.627 | 14.306 | p<0.001 |
| Intercept | 133.327 | 1 | 133.327 | 151.046 | p<0.001 |
| Degree of patient involvement | 17.877 | 1 | 17.877 | 20.253 | p<0.001 |
| Facilitators' experience×degree of patient involvement | 3.662 | 1 | 3.662 | 4.149 | p<0.05 |
| Error | 105.040 | 119 | 0.883 | | |
| Total | 1590.000 | 122 | | | |
| Corrected total | 130.295 | 121 | | | |

* $r^2=0.194$ (adjusted $r^2=0.180$).

Table 3 Regression results for power relations

| Source | Type III sum of squares | df | Mean square | F | Significance |
|---|-------------------------|-----|-------------|--------|--------------|
| Corrected model | 34.576* | 2 | 17.288 | 15.089 | p<0.001 |
| Intercept | 88.352 | 1 | 88.352 | 77.113 | p<0.001 |
| Degree of patient involvement | 25.139 | 1 | 25.139 | 21.941 | p<0.001 |
| Facilitators' experiences×degree of patient involvement | 4.368 | 1 | 4.368 | 3.813 | p=0.053 |
| Error | 137.489 | 120 | 1.146 | | |
| Total | 1396.000 | 123 | | | |
| Corrected total | 172.065 | 122 | | | |

* $r^2=0.201$ (adjusted $r^2=0.188$).

roles, and hence their power position, are strengthened. This is supportive of Donetto *et al*,⁶³ arguing that the patient role is strengthened by involving the patients in QI. Therefore, the results also support the relationship management literature in that two separate actors share and leverage each other's resources.^{53 58}

Second, the study revealed that if projects are led by someone with experience in leading QI projects with patients involved, this has a moderating effect on patient involvement on a strengthened patient role. Thus, this study provides empirical evidence supporting Batalden and Stoltz's⁵⁵ view on improvement science being a competence area of its own, which is needed for healthcare professionals working with QI. If healthcare professionals facilitating improvements have insights in improvement science in combination with their professional knowledge, trust and confidence in QI are supported.^{3 64} As shown in this study, using professionals with experience from the area of improvement science as leaders of QI projects will be a way to further leverage the effect of patient involvement on a strengthened patient role.

Third, with respect to a movement from a professional-dominated relationship to an interdependent one (referring back to figure 2), the results are in line with previous research^{51 63} in that patient involvement contributes to such a movement. As knowledge and power are intertwined,^{43 44} access to the knowledge production is essential and involving patients as cocreators in QI may be the way forward to address asymmetric power relationships.⁴⁷ Departing from the upper left-hand side, Armstrong *et al*⁴³ state that the unequal relationship between healthcare professionals and patients favours the healthcare professionals. Moreover, it is argued¹³ that the current power relationship hinders patient involvement. Interestingly, though, when working together with QI, the traditional relationship between patients and healthcare professionals is challenged.^{30 65} This study points to two components that can support a shift towards a more balanced and interdependent power relationship (figure 1, upper right-hand side). First, by patient involvement in QI, unique knowledge, skills and experience from both patients and healthcare professionals are exploited. Involving patients as cocreators in QI could

hence be a way of reshaping the relationship between patients and healthcare professionals. For this to happen, a certain degree of acceptance of interdependence by both parties is needed.⁵⁹ Such an interdependent position is beneficial as it creates a situation where collaborative and cocreative approaches, as well as leverage of knowledge on both actors' side, are possible.⁵⁶ Second, this study implies that a more power-balanced relation is achieved by extending the knowledge base of the professional not only by insights in improvement science⁵⁵ but also by a change in the capture and sharing of value⁵³ that occurs when patients become cocreators in QI.

Strengths and limitations

This study is limited to healthcare professionals' perceptions and experiences about QI based on patient involvement; further studies from the patient perspective are encouraged. One such area is to capture and investigate the experiences from patients and relatives about being involved in QI in healthcare and to study the effects on quality in care processes. Moreover, changes supporting patient involvement take place in a complex system in which this study has centred on the patient–professional relation; further studies could be extended to include other influential determinants, such as the system antecedents for change,³⁶ for example, leadership, managerial relations and organisational maturity. Despite these limitations, the main strength of this study is to identify interdependence as a professional–patient power position creates favourable conditions for a cocreation of QI.

CONCLUSION

Increased patient involvement in QI is a means of strengthening the patient role and supporting a more equal relation between patients and healthcare professionals. Furthermore, the healthcare professionals' experiences in the area of improvement science moderate the effect of the degree of patient involvement in a strengthened patient role and a more equal power relationship. This paper suggests that to fully exploit the potential of this shift, the synergies of combining the knowledge bases of both healthcare professionals and patients need

to be acknowledged. Policymakers should thus support healthcare systems that recognise the input from a variety of actors in developing healthcare services. Moreover, the paper also points to the necessity to reach a state of interdependence between actors to enable the mutual goals of the QI. In other words, to gain as many benefits as possible from QI, it needs to be practiced not only as a dual actor but also as a bidirectional effort.

Contributors IG, ME and SG developed and directed the survey. ME performed the statistical analysis. IG, EE, AH and FS designed this specific study and did the draft and editing of the manuscript. ME and SG provided input on the manuscript. All authors approved the manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, conduct, reporting or dissemination plans of this research.

Patient consent for publication Not required.

Ethics approval This study is in harmony with the ethical code of research in healthcare. No formal ethical approval was needed.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. The database is held at the host institution and analysis and access to the data are limited to on-site access. More detailed analyses are available on request from the corresponding author.

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REFERENCES

- Berwick DM. The science of improvement. *JAMA* 2008;299:1182–4.
- Mintzberg H. *Managing the myths of health care: bridging the separations between care, cure, control, and community*. Berrett-Koehler Publishers, 2017.
- Bergman B, Hellström A, Lifvergren S, et al. An emerging science of improvement in health care. *Qual Eng* 2015;27:17–34.
- Haw C, Collyer J, Sugarman P. Patients' complaints at a large psychiatric Hospital: can they lead to better patient services? *Int J Health Care Qual Assur* 2010;23:400–9.
- Holman H, Lorig K. Patients as partners in managing chronic disease. partnership is a prerequisite for effective and efficient health care. *BMJ* 2000;320:526–7.
- Wofford MM, Wofford JL, Bothra J, et al. Patient complaints about physician behaviors: a qualitative study. *Acad Med* 2004;79:134–8.
- Eriksson EM, Raharjo N, Gustavsson S. Exploring complaints by female and male patients at Swedish hospitals using a probabilistic graphical model. *Scand J Caring Sci* 2018;32:1148–56.
- Fallowfield L, Jenkins V. Effective communication skills are the key to good cancer care. *Eur J Cancer* 1999;35:1592–7.
- Olsson EM. Interpersonal complaints regarding cancer care through a gender lens. *Int J Health Care Qual Assur* 2016;29:687–702.
- Wessel M, Lynøe N, Juth N, et al. The tip of an iceberg? A cross-sectional study of the general public's experiences of reporting healthcare complaints in Stockholm, Sweden. *BMJ Open* 2012;2:e000489.
- Gallan A, Burke Jarvis C, Brown S, et al. Customer positivity and participation in services: an empirical test in a health care context. *Academy of Marketing Science* 2013;41:338–56.
- Greene O, Lombarts MJMH, Klazinga N, et al. Is patient-centredness in European hospitals related to existing quality improvement strategies? analysis of a cross-sectional survey (Marquis study). *Qual Saf Health Care* 2009;18 Suppl 1:i44–50.
- Armstrong N, Herbert G, Aveling E-L, et al. Optimizing patient involvement in quality improvement. *Health Expect* 2013;16:e36–47.
- Wiig S, Storm M, Aase K, et al. Investigating the use of patient involvement and patient experience in quality improvement in Norway: rhetoric or reality? *BMC Health Serv Res* 2013;13:206.
- Maher LM, Hayward B, Hayward P, et al. Increasing patient engagement in healthcare service design: a qualitative evaluation of a co-design programme in New Zealand. *Patient Exp J* 2017;4:23–32.
- Barry CA, Stevenson FA, Britten N, et al. Giving voice to the lifeworld. more humane, more effective medical care? A qualitative study of doctor-patient communication in general practice. *Soc Sci Med* 2001;53:487–505.
- Greenhalgh T, Robb N, Scambler G. Communicative and strategic action in interpreted consultations in primary health care: a Habermasian perspective. *Soc Sci Med* 2006;63:1170–87.
- Olsson E, Lau M, Lifvergren S, et al. Community collaboration to increase foreign-born women's participation in a cervical cancer screening program in Sweden: a quality improvement project. *Int J Equity Health* 2014;13:62–72.
- Schoen C, Osborn R, Squires D, et al. New 2011 survey of patients with complex care needs in eleven countries finds that care is often poorly coordinated. *Health Aff* 2011;30:2437–48.
- SKL (Sveriges Kommuner och Landsting). *Svensk sjukvård i internationell jämförelse ('Swedish healthcare in international comparison')* 2015:ISBN 978-91-7585.
- Vårdanalys. *Vården ur patienternas perspektiv: Jämförelser mellan Sverige och tio andra länder ('Healthcare from the patients' perspectives'). Rapport 2014:11*. Stockholm: TMG, 2014.
- Bohmer R. *Designing care: aligning the nature and management of health care*. Watertown, MA: Harvard Business School Press, 2009.
- Luxford K, Safran DG, Delbanco T. Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *Int J Qual Health Care* 2011;23:510–5.
- Lombarts MJMH, Rupp I, Vallejo P, et al. Application of quality improvement strategies in 389 European hospitals: results of the Marquis project. *Qual Saf Health Care* 2009;18 Suppl 1:i28–37.
- Berry LL, Bendapudi N. Health care: a fertile field for service research. *J Serv Res* 2007;10:111–22.
- Batalden M, Batalden P, Margolis P, et al. Coproduction of healthcare service. *BMJ Qual Saf* 2016;25:bmjqs-2015.
- Hardyman W, Daunt KL, Kitchener M. Value co-creation through patient engagement in health care: a micro-level approach and research agenda. *Public Manag Rev* 2015;17:90–107.
- Bate P, Robert G. Toward more User-Centric od: lessons from the field of experience-based design and a case study. *J Appl Behav Sci* 2006;43:41–66.
- Elg M, Engström J, Witell L, et al. Co-creation and learning in health-care service development. *J Serv Manag* 2012;23:328–43.
- Smith F, Wallengren C, Öhlén J. Participatory design in education materials in a health care context. *Action Res* 2017;15:310–36.
- Osborne SP, Radnor Z, Kinder T, et al. The service framework: a Public-service-dominant approach to sustainable public services. *Brit J Manage* 2015;26:424–38.
- Berwick D. What “patient-centered” should mean: Confessions of an extremist. *Health Affairs* 2009;28:555–65.
- Lifvergren S, Huzzard T, Hellström A. Editorial. *Action Res* 2015;13:3–8.
- Balazs CL, Morello-Frosch R. The three RS: how community-based participatory research strengthens the rigor, relevance, and reach of science. *Environ Justice* 2013;6:9–16.
- Gremyr I, Elg M, Smith F, et al. Exploring the phase for highest impact on radicality: a cross-sectional study of patient involvement in quality improvement in Swedish healthcare. *BMJ Open* 2018;8:e021958.
- Greenhalgh T, Robert G, Macfarlane F, et al. Diffusion of innovations in service organizations: systematic review and recommendations. *Milbank Q* 2004;82:581–629.
- Gidman W, Ward P, McGregor L. Understanding public trust in services provided by community pharmacists relative to those provided by general practitioners: a qualitative study. *BMJ Open* 2012;2:e000939.
- Vargo SL, Lusch RF. Service-dominant logic: continuing the evolution. *J Acad Mark Sci* 2008;36:1–10.
- Grönroos C. *Service management and marketing: managing the service profit logic*. John Wiley & Sons, Incorporated, 2015.
- Gaventa J, Cornwall A. Power and knowledge the SAGE Handbook of action research: participative inquiry and practice 2008;2:172–89.
- Visser LM, Bleijenbergh IL, Benschop YWM, et al. Do online communities change power processes in healthcare? using case studies to examine the use of online health communities by patients with Parkinson's disease. *BMJ Open* 2016;6:e021110.

- 42 Lukes S. *Power: a radical view*. Macmillan International Higher Education, 2004.
- 43 Foucault M. The subject and power. *Crit Inq* 1982;8:777–95.
- 44 Foucault M. *Diskursens ordning. Inaugural lecture at Collège de France December 2, 1970 ('The order of discourse')*. Stockholm: Brutus Östlings Symposium, 1993.
- 45 Fernandes Agreli H, Murphy M, Creedon S, *et al*. Patient involvement in the implementation of infection prevention and control guidelines and associated interventions: a scoping review. *BMJ Open* 2019;9:e025824.
- 46 Nordgren L. Value creation in health care services – developing service productivity. *Int J Public Sect Manag* 2009;22:114–27.
- 47 Fals-Borda O. Some basic ingredients. In: Fals-Borda O, Rahman M, eds. *Action and knowledge: breaking the monopoly with participatory action-research*. New York: Apex Press, 1991: 3–12.
- 48 Robert G, Cornwell J, Locock L, *et al*. Patients and healthcare professionals as co-designers of healthcare services. *BMJ* 2015;350:g7714.
- 49 Ekman I, Swedberg K, Taft C, *et al*. Person-centered care--ready for prime time. *Eur J Cardiovasc Nurs* 2011;10:248–51.
- 50 Donetto S, Tsianakas V, Robert G. *Using experience-based Co-design (EBCD) to improve the quality of healthcare: mapping where we are now and establishing future directions*. London: King's College London, 2014.
- 51 Lord L, Gale N. Subjective experience or objective process. *J Health Organ Manag* 2014;28:714–30.
- 52 Tsianakas V, Robert G, Maben J, *et al*. Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. support cancer care 2012.
- 53 Rehme J, Nordigården D, Ellström D, *et al*. Power in distribution channels — supplier assortment strategy for balancing power. *Ind Mark Manag* 2016;54:176–87.
- 54 Emerson RM. Power-Dependence relations, American sociological review 1962;27:31–41.
- 55 Batalden PB, Stoltz PK. A framework for the continual improvement of health care: building and applying professional and improvement knowledge to test changes in daily work. *Jt Comm J Qual Improv* 1993;19:424–47.
- 56 Cox A. The art of the possible: relationship management in power regimes and supply chains. *Supply Chain Manag* 2004;9:346–56.
- 57 Ford D. The development of Buyer-Seller Relationships in Industrial Markets. In: Ford D, ed. *Understanding business markets*. London: The Dryden Press, 1997.
- 58 Gadde L-E, Håkansson H, Persson G. *Supply network strategies*. Chichester: Wiley, 2010.
- 59 Caniëls MCJ, Gelderman CJ. Power and interdependence in buyer supplier relationships: a purchasing portfolio approach. *Ind Mark Manag* 2007;36:219–29.
- 60 Smith F, Alexandersson P, Bergman B, *et al*. Fourteen years of quality improvement education in healthcare: a utilisation-focused evaluation using concept mapping. *BMJ Open Qual* 2019;8:e000795.
- 61 Andersson A-C, Elg M, Perseus K-I, *et al*. Evaluating a questionnaire to measure improvement initiatives in Swedish healthcare. *BMC Health Serv Res* 2013;13:48.
- 62 Gustafsson A, Kristensson P, Witell L. Customer co-creation in service innovation: a matter of communication? *J Serv Manag* 2012;23:311–27.
- 63 Donetto S, Pierri P, Tsianakas V, *et al*. Experience-Based Co-design and healthcare improvement: realizing participatory design in the public sector. *Int J Des* 2015;18:227–48.
- 64 Godfrey MM, Andersson-Gare B, Nelson EC, *et al*. Coaching interprofessional health care improvement teams: the coachee, the coach and the leader perspectives. *J Nurs Manag* 2014;22:452–64.
- 65 Gustavsson S, Andersson T. Patient involvement 2.0: experience-based co-design supported by action research. *Action Research Journal* 2017.