ORIGINAL RESEARCH

The Perceptions of Health Care Team Members About Engaging Patients in Care Redesign

Study findings support the inclusion of patient representatives on TCAB teams.

There has been considerable support recently for greater engagement by patients and their families, both in decisions about the patients' own care and in the policy decisions of health care organizations.[1, 2] And patients can make valuable contributions to the process of care redesign. During their care, they witness much or all of the health care process, and their experiences may include inconsistencies in care, errors, and adverse events.[3, 4] Furthermore, patients with chronic illnesses become experts "not only on their own disease and its treatment but also on the frailties, limitations and unintentional cruelties of their health care system."[4] Their experiences may include information that can't be captured by quantitative measurements—and such information might serve as a catalyst for change or an instrument for learning.[5]

Decision makers and researchers agree on the importance of increasing patient engagement in health care.[6, 7] But neither the American nor the Canadian health care system is structured to elicit patient participation at the organizational level, and making the necessary changes to include patients and support them appropriately poses a challenge.[6, 7] We need a better understanding of both how to foster patient engagement and how such engagement affects decision making and the quality of care. Very few studies have specifically addressed the views of patients and providers on patient engagement.[8] To learn more, we conducted a study at a Canadian university–affiliated health care center among health care providers and managers who engaged patients in a care redesign process under a program called Transforming Care at the Bedside (TCAB). This article reports on our findings.

BACKGROUND

Engaging patients in care redesign. Patient engagement is increasingly being recognized as critical to improving the quality, safety, and delivery of health care and to promoting both optimal health care and patient experiences.[2, 9] The Canadian Health Services Research Foundation (CHSRF; now known as the Canadian Foundation for Healthcare Improvement) has described the health care system as inherently so complex that different perspectives are needed to improve it.[10] In order for a given practice change to be effective, the perspectives of both providers and patients must be considered, and patients should be committed to the change.[11] Moreover, incorporating patients' suggestions may increase their acceptance and use of that change.[12]

As Bergeson and Dean have noted, "Most systems that support clinicians would benefit from redesign that aligns care more completely with patients' needs and interests."[13] Working collaboratively with patients allows providers to clarify and understand the issues before generating solutions, increasing the likelihood of effective resolution.[14] Engaging both patients and providers has also been shown to facilitate care redesign aimed at providing culturally competent care.[15]

Barriers. A variety of barriers stand in the way of efforts to increase patient participation in care redesign. In a report on their environmental scan,

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ABSTRACT

Objective: This study sought to explore the perceptions of health care workers about engaging patients as partners on care redesign teams under a program called Transforming Care at the Bedside (TCAB), and to examine the facilitating factors, barriers, and effects of such engagement.

Design: This descriptive, qualitative study collected data through focus groups and individual interviews. Participants included health care providers and managers from five units at three hospitals in a university-affiliated health care center in Canada.

Methods: A total of nine focus groups and 13 individual interviews were conducted in April 2012, 18 months after the TCAB program began in September 2010. Content analysis was used to analyze the qualitative data.

Findings: Health care providers and managers benefited from engaging patients in the decision-making process because the patients brought a new point of view. Involving the patients exposed team members to valuable information that they hadn't previously thought about during decision making.

Conclusion: Health care teams stand to benefit from engaging patients in the change process. Patients contribute a different point of view, and this helps to ensure that the changes proposed and implemented address their needs.

Keywords: care redesign, health care team, patient engagement, Transforming Care at the Bedside

Maurer and colleagues identified barriers to patient and family engagement as "fear, uncertainty, low health literacy, and provider reactions."[8] For providers, barriers to supporting such engagement included "professional norms and experiences, fear of litigation, and perceived level of effort."[8]

Gagliardi and colleagues conducted a qualitative study to explore patient and provider perspectives about including patients in performance indicator selection.[16] Most providers believed that patients should be consulted but should not be included in decision making. Providers also felt it was difficult to engage patients because of "a lack of guidance for appropriate mechanisms" by which to do so. Similarly, Steele and colleagues recognized that, in their care redesign efforts for an advanced medical home model, they lacked adequate patient engagement tools.[17] Another barrier is the inconsistency of provider attitudes toward patient participation.[3] A literature review by Cahill found that nurses and physicians reported "mixed" sentiments about its value and desirability.[18] And Luxford and colleagues identified difficulty in shifting providers' mindset from provider-focused to patient-focused as a barrier.[5]

Gagliardi and colleagues also found that patients over 70 years of age showed little interest in participating in care redesign, and noted similar findings in the literature.[16] As Kvarnstrom and colleagues have reported, "[S]ervice users' preferences for participation . . . are not uniform, ranging from passive to more active roles" and varying according to age and social status.[19]

A pretest–posttest study by Forbat and colleagues explored the effects of a collaborative care redesign project on participants' attitudes and behaviors; the participants included health care professionals, patients who had received treatment for lung cancer, and patients' family members.[20] Patients involved in care redesign felt that they were seen as being "more healthy, articulate and educated, and having the time and resources to participate." But patients also raised concerns about the power imbalance between providers and patients, indicating that they felt their input was "unwanted or unwelcome." Some felt that providers were apathetic about serving on the redesign committee. Physical and organizational barriers to participation, such as illness-related debilitation and difficulties obtaining transportation, were also noted.

Facilitating factors. In their report, Maurer and colleagues identified facilitating factors to patient and family engagement as "self-efficacy, information, invitations to engage, and provider support."[8] Forbat and colleagues noted the importance of three ideas: empowering patients to express their views; having someone outside the clinical area lead the collaborative effort, in order to promote openness; and clarifying the roles of all participants.[20] Indeed, in collaborative efforts, it's essential that all those involved understand and agree on each person's role.[21] Having providers who "champion" patient engagement has been identified as a facilitating factor.[16] There is evidence that the amount of time providers invest in working with patients also matters.[16] Time fosters the development of trust; and trust is maintained when involvement is continuous and when staff "spend much of their time listening and [are] judicious in offering opinions."[22]

According to Sodomka, the "single most important guideline for involving patients and families in any advisory role is to believe that their participation is essential to the design and delivery of optimum care and services."[23] To encourage that belief, leaders should create a safe, friendly environment that conveys understanding and respect for diverse cultural beliefs, socioeconomic statuses, and health literacy levels.[24] Existing systems and structures may need to be altered to facilitate partnership, transparency, and information sharing.[25] Health care professionals and patients alike may need training in effective communication (such as active listening) and shared decision-making skills.[21] Sufficient resource allocation for care redesign is also necessary.[5, 16]

> 'If we're gonna make changes that impact [patients], I think we have to get them involved.'

Engaging patients through the TCAB initiative. In 2003, the Robert Wood Johnson Foundation and the Institute for Healthcare Improvement (IHI) jointly developed and launched the TCAB initiative in the United States.[26] It is rooted in the idea of continuous quality improvement; its overarching purpose is to inspire and empower frontline nurses and managers to make changes that transform bedside care.[27]

In 2010, the CHSRF launched the Patient Engagement Projects (PEP) initiative.[6] This initiative "supports 17 health leaders across Canada who are either involving patients in decisions about service design and delivery or increasing patients' capacity for engaging more meaningfully in such decision-making."[28] With financial support from the CHSRF's PEP program and in collaboration with the IHI, in 2010 McGill University Health Centre (MUHC) in Montreal launched a TCAB initiative on five units at three of its hospitals.[29] This was one of the first TCAB initiatives in Canada.

The TCAB program sets out five objectives ("pillars") and provides the tools and techniques to achieve these objectives.[26] The five objectives are[30]:

- improving care quality and safety
- increasing vitality and teamwork
- improving patients' and family members' experience of care
- maintaining value-added care processes
- developing transformational leadership competencies

While TCAB teams are interdisciplinary, nurses play an essential role. TCAB seeks to empower frontline caregivers, particularly staff nurses, such that they can "identify problems on their units, develop testable strategies for improvement, and develop their leadership skills to lead further system change."[31] Between 2005 and 2008, Parkerton and colleagues conducted an evaluation of TCAB implementation at 13 U.S. pilot facilities.[32] In describing their results, they stated that "the findings suggest that a well-instituted, complex intervention to engage frontline staff in quality improvement can successfully change work processes and relationships and lead to a more open learning environment." They also observed that although TCAB relies on the involvement of all frontline nurses, the actions of nurse leaders were especially critical: "engaging in a management style that ceded some authority to staff nurses, supported the development of new skills in staff members, and fostered more effective staff problem solving" was vital to successful implementation. The findings of a related evaluation by Pearson and colleagues of 17 nursing units participating in TCAB also confirmed the importance of transformative leadership.[33] With senior leadership supporting unit-level responsibility and facilitating staff participation, frontline nurses became involved: "half of the hospitals reported that 80% or more of their frontline nurses were participating."

TCAB AT MUHC

The program that was launched on the five units at three MUHC hospitals differed notably from the original TCAB program, in that patients were directly and deliberately embedded on the care redesign teams.[29] The five units included an internal medicine unit; a neurosurgical unit; a gynecology–oncology unit; a psychiatric unit; and a multiservice, general surgical unit. On each of these units, a TCAB team was created. Each team consisted of frontline caregivers from different disciplines, managers, assistant managers, patient representatives, and a TCAB facilitator. The goal was to engage patients, families, and staff in redesigning inpatient care delivery processes in order to achieve the necessary improvements and meet the real needs of patients and families. Patient representatives were recruited from the hospitals' patient committees, whose members are either former patients or former patients' family members. There were no specific qualifications; but time was sometimes a factor. Patient representatives were invited to participate for half a day each week for a long period. Sometimes the day chosen by the unit was an obstacle to their participation.

In August 2010, the TCAB teams began work by learning rapid-cycle improvement processes and testing improvement ideas. From September 1, 2011, to June 1, 2012, the teams worked on three distinct modules: module 1, improving the physical work environment using the "Lean 5S" process improvement methods (sort, set in order, shine, standardize, sustain)[34]; module 2, improving the patients' experience of care; and module 3, improving admission and discharge processes using process mapping techniques. Each module lasted approximately 10 to 12 weeks. Full-day intensive training workshops were given to the TCAB team at the start and end of each module. The patient representatives joined in all of the discussions, planning, and actions of the TCAB teams. They were involved with patients currently hospitalized on their unit and contributed to TCAB activities in several ways. These activities included explaining the care redesign efforts to patients, seeking patients' feedback about tested changes, developing and conducting surveys, reviewing the nursing admission database, creating a "Welcome to the Unit" pamphlet for patients and families, addressing patients' health literacy issues, redesigning the family room, improving the discharge process, and generally helping patients to become more engaged in their health plans and treatment.

During focus groups, patient representatives expressed feeling fully integrated into the TCAB teams and feeling that their input was valued.[35] They reported feeling that their partnership was necessary to the TCAB process and to the true picture of the situation. They mentioned key elements of a collaborative partnership between patients and health care professionals such as good listening, trust, openness, transparency, collaboration, and mutual respect. But it's clear that more research is needed. A systematic review by Mockford and colleagues sought to identify the impact of "patient and public involvement" in care redesign.[36] They found that while such involvement had "a range of impacts on healthcare services," the evidence was limited by the overall poor quality of reporting, and they called for more exacting research. And our literature search yielded little information specifically about providers' perceptions of patient involvement in care redesign. Thus, in this study, we aimed to explore the perceptions of health care providers and managers in engaging patients as partners on TCAB care redesign teams and to examine the facilitating factors, barriers, and effects.

Including patient representatives on the TCAB team ensures that they, as well as other team members, are equipped with the tools, training, and coaching vital to implementing change.

Over 120 tests of change were conducted by the five unit TCAB teams, using "plan–do–study–act" rapid-cycle improvement processes to improve care or the work environment. Unit staff and patient representatives identified the problems they wanted to address, conducted multiple tests of change using simple measurements, and evaluated the impact of tested changes on care effectiveness, care efficiency, patient satisfaction, or staff satisfaction. Then they reported the results at both the unit and organizational levels. Examples of tested changes include a redesigned admission process on the psychiatric unit; equipment and supply relocation to improve efficiency; the introduction of whiteboards at bedsides to improve communication between patients and providers; standardization of patient education tools, documentation systems, and handoff processes; the use of visual triggers to shorten bed turnover times; and the creation of quiet zones to reduce medication interruptions and transcription errors.

METHODS

Design. This descriptive, qualitative study collected data through focus groups and individual interviews. Participants included managers and hospital workers from five TCAB units at MUHC in Montreal.

Procedure. Ethical approval was obtained from the organization's ethical review board. A purposive sampling approach was used to recruit health care providers and managers from among the TCAB teams and team units. One member of the research team (MLT) presented the study to teams from each unit, and two focus group dates were proposed per unit to obtain 10 to 15 participants per unit. Individual interviews were scheduled with managers and providers who could not attend a focus group because of schedule conflicts. Before each focus group and interview, the study was explained verbally by a research team member (MLT, GC, or both), and participants gave their informed, written consent. To protect

Table 1. Profession and Work Experience of Participants (N = 73)

Profession and Work Schedule	No. of Responses (%)
Profession	
Nurse	33 (45)
Manager	11 (15)
Patient attendant	7 (10)
Occupational therapist	5 (7)
Physician	4 (5)
Physiotherapist	4 (5)
Social worker	3 (4)
Unit coordinator	2 (3)
Other	4 (5)
Work schedule[a]	
Full time	62 (85)
Part time	9 (12)
Work Experience	**No. of Years, average**
In current position	8 (range, 4 mo–29 y)
Overall	15 (range, 4 mo–38 y)

[a] Number of participants do not sum to 73 because two worked on a casual basis.

confidentiality, each participant was identified by a code. The focus groups and interviews lasted 45 minutes and were conducted at the participants' organization by a research team member (MLT, GC, or both).

Data collection. A total of nine focus groups involving 60 participants and 13 individual interviews were conducted in April 2012, 18 months after the TCAB teams began work. An interview guide served as the data collection tool for the interviews and focus groups. Sociodemographic profiles were developed at the start of each individual interview and focus group session.

The main themes of the interview guide were based on the implementation analysis strategy described by Denis and Champagne,[37] and focused on the start-up context and the level and impact of patient engagement. (The implementation analysis strategy implies that a relationship exists between the context in which an intervention occurs, the implementation of the intervention, and the effects of the intervention.[37, 38]) The following is an example of the kinds of questions asked under each theme.

- How have the TCAB teams worked with patient and family engagement so far? How are the patient representatives involved? Can you give me an example? Can you describe the level of patient engagement?
- What impact do you think their involvement has had? How would you explain this impact?
- What could be done to facilitate their engagement?

Data analysis. Because the study was descriptive in nature, data analysis was primarily guided by the interview questions, rather than by a specific theoretical paradigm. Interviews were audio-recorded and transcribed. The data generated by the interviews and focus groups were analyzed using NVivo 7, according to the method proposed by Miles and Huberman, which involves three concurrent streams of activities: condensing the data (coding of individual interview data to identify major themes and categories), presenting the data (data display of themes from all interviews), and elaborating on and verifying the data.[39] Member checking was done during the individual interviews with the participants to establish data credibility. Two researchers (MLT and GC) independently coded the transcripts from a set of data to ensure consensus and to reduce the possibility of biased interpretation. The analyzed data were discussed with the research team to establish a consensus that the analysis was representative of the phenomenon studied. An audit trail was used to keep a record of details concerning data collection and decision making during the study. Demographic information was collected to allow for an external assessment of the generalizability of the findings to another setting.

RESULTS

Participants. In all, there were 73 participants: 62 women (85%) and 11 men (15%). The average age was 40.5 years. Among the participants, four (5%) had a doctoral level or medical degree, 14 (19%) had a master's degree, 32 (44%) had a bachelor's degree, and 23 (32%) had a technical or preuniversity education. Participants' overall work experience averaged 15 years (range, 4 months to 38 years). For more on participants' professions and work experience, see Table 1.

The common themes that emerged from the interviews were grouped into four major categories: patients' contribution to the decision-making process, facilitating factors and barriers to patient engagement, impact of patient engagement in TCAB, and recommendations.

Patients' contribution to the decision-making process. Participants described the importance of engaging current inpatients, their family members, and patient representatives to ensure that they contributed to decisions made about changes sought through TCAB. Some noted that providers are "comfortable" with their health care teams, and that adding patient representatives exposed them to valuable information that they hadn't previously thought about during decision making.

> I think the whole thing is we're trying to improve care. It's all about them [current inpatients] anyways. So if we're gonna make changes that impact them I think we have to get them involved. I mean, they have to . . . basically be a crucial part of the whole decision and the whole process. So to get their input

> and to know what's best for them. I mean . . . What they're missing? What they need? What they want, like the information? Anything regarding them.
>
> It gets them involved . . . they don't just see us as making all the decisions. It gives them, I guess, a way to communicate their ideas, their feelings about certain things . . . because at least, once you asked the patient and the family how they feel about something then, we can refocus ourselves into, making it better for them. . . . It's very important to the family members to give us input.
>
> I think it's a good thing. . . . After all, patients have good ideas. And sometimes their point of view is a little different than a care provider, but they never had a say, there are things that no one realized, that means something to patients.
>
> Because at first, when I heard patient rep, I'm thinking oh my god! We're gonna expose ourselves, to strangers . . . because our practice was so that we work with our team. We work with ourselves. We're comfortable as a health care team. We speak the same language or so we think. That's the perception. So to bring a patient in, you're thinking oh my god! I'm exposing all of myself so they'll see all of my imperfections . . . that was at the back of my mind at first, but then once they're there, you're thinking wow! It's great having them because they have input and they have valuable information that you can use.

Facilitating factors and barriers to patient engagement. Participants reported using various methods of communication to facilitate engagement by current inpatients. These methods included whiteboards, questionnaires, direct discussion, or communication through patient representatives.

> We did a lot of patient interviews. We involved them with . . . even starting with Module 1 when we did our patient information board, we ask the patients and the family members to know what information they would like to have on their board and to see . . . 'cause we had our own ideas of what should be on there . . . then we realized we really have to start from them and get their input first and see what's best for them.
>
> The whiteboards provoked discussions with patients and families. They're very curious and we find that they really enjoy using the whiteboard. And what's very helpful too, simply telling the patient your name in the morning. But during the course of the day they see so many people and so they often cannot keep track of individuals' names. So sometimes if you go and . . . to do a follow-up for instance, and you ask the patient: what's the name of your nurse? They quickly look at the board. And they can tell.
>
> But also, we ask a lot of information and to current inpatients specifically what they would like to know more about. Discharge planning or other stuff like medication . . . some basis on that we try to work more and more what would be the best information.

'I would say that it's a good idea to include a patient representative on the team . . . from the start.'

According to participants, some modules were more conducive to engaging current inpatients or patient representatives in TCAB because the module's focus affected them more directly. For example, improving the physical work environment (module 1) was somewhat less conducive to patient engagement than module 2 (improving the patients' experience of care).

> Because Module 2 was patient experience of care. So we were able to involve them a lot more than the first module. It was just the physical environment of work . . . I think once we got Module 2 . . . once we got into the patients' experience. The whiteboard . . . and they got really involved with . . . But they also got involved directly with patients and families with their surveys and questionnaires that really helped them understand their role.
>
> Well, Module 2 was patient engagement. So we really tried to involve them in all the decisions.

Participants reported finding it easier to work alongside patient representatives who had some experience and expertise, especially in the health field, perhaps because it was easier for them to establish their role on the team. They also found it easier when the representative was open-minded and wanted to be involved.

> What helped engage the patients and the families? She's [the patient representative] involved already like she wanted to be involved and she was ready to do like if we asked her to do a survey she was ready to do it right away. So. Open-minded.

> She's been very helpful actually. She has a lot of insights, so sometimes we think one thing, but she has a different perspective from the patients so that's helpful. It stops us a little bit and makes us think a little bit differently . . . she's understanding from our perspective.

Patients were receiving care that was more adequate and better suited to their needs.

According to participants, patient representatives' own health problems or physical limitations were the greatest barrier to their participation.

> We created a new pamphlet, information pamphlet, that we wanted her input . . . She missed a few [reunion meetings] because she got either ill or she had appointments.

> It's sad to say, but our patient rep they're wheelchair-bound so for [our] working physical environment it was very difficult for them.

> [One] patient rep, she's less involved. She doesn't come all the time and her health status also does not . . . I think blocking her a little bit from being as involved as the other ones so. But when she comes, like I mean, she really helps and it's great too. It's just we have less of her input.

Impact of patient engagement in TCAB. Participants reported that current inpatients and family members were better informed and had received the information they really wanted. They also indicated that patients were receiving care that was more adequate and better suited to their needs.

> I think that the more the patients are informed of what is happening, the better it is. Because they know where they are going. They have more confidence in what is happening and this sometimes may result in less conflicts, like when they say, I don't know what is happening; they made a mistake on the medication. They are also responsible for watching and seeing what's going—more than just seeing, communicating. This makes things easier in the long run.

> Well, I think it meets their needs better because we, as care providers, we might have an idea of what patients need, but when you take a second look, sometimes you run into little surprises.

> Well, we've had excellent feedback from the patient reps. So I think that was valuable having them on board. I don't think it would be the same if there was no patient rep. And it was just a perspective, but it was very good having them as part of that project as well . . . they had a lot of good ideas and great feedback for us. So that helped us a lot to progress with that part . . . sometimes we stuck on something while we're planning and it's very easy to say well, let's ask the patient rep and see what, what they think.

Recommendations. Participants recommended that patient representatives become involved earlier, from the start of a TCAB program, in order to plan changes more effectively.

> What I would tell you is that you need to get them on board. It's very important because they have a lot of information that you might not even think about. And so they're very helpful in the planning of whatever you want to do. So I would say get them on board from the beginning.

> I would maybe say that they should form an alliance with a patient representative . . . even before conducting a study of the entire patient clientele. When you have a patient representative's point of view, you already have a good idea where things are headed. So it might save time, or better make sure that everyone is on the same page. I would say that it's a good idea to include a patient representative on the team because of that. From the start.

DISCUSSION

The findings show that TCAB teams benefit from involving patients as partners in the care redesign process. In our study, health care providers and managers perceived that patients brought unique viewpoints and valuable information and suggestions to the decision-making process. This helped the TCAB teams to plan changes and offer care that better met patients' and families' needs.

As Zarubi and colleagues have observed, empowering patients to question existing policies and practices initiates a process whereby providers "stop, question our objectives, and evaluate whether there is a better way to meet them."[22] Furthermore, including patient representatives on the TCAB team ensures that they, as well as other team members, are equipped with the tools, training, and coaching vital to implementing change. This may be why many barriers to patient engagement that have been identified in the literature—such as insufficient guidance, inadequate tools, and a lack of mechanisms for involvement[16, 17]—were not mentioned by participants in our study. As Leonhardt pointed out, both providers and patients need training in the skills required for effective communication and shared decision making.[21] Forbat and colleagues commented on the advantages of including an independent facilitator to lead patient involvement.[20] These suggestions were implemented under this TCAB initiative. It seems reasonable to assume that such training and facilitation played important roles in our teams' success in engaging patients.

Our participants did identify patient representatives' own health problems or physical limitations as a barrier to engagement. This finding is consistent with the results of a pretest–posttest study by Forbat and colleagues.[20] We found that having two to three patient representatives embedded on each unit's TCAB team helped to offset this barrier. Also, patient representatives whose illnesses forced their absence for a time often stayed in contact via e-mail with the unit manager.

Our findings demonstrate the importance of involving patients from the outset of a TCAB initiative. At the time of our interviews, the patient representatives and health care providers and managers had been working together for over 18 months. As Gagliardi and colleagues noted, the length of time that providers work with patients has an impact on providers' acceptance of the patients' role.[16] And to expand on what Sodomka suggested, perhaps the most important facilitating factor in including patients on care redesign teams is for *all* those involved to believe that their participation is crucial to improving the design and delivery of services.[23]

Limitations. This study was conducted on five units at hospitals that were all part of one health care organization. Therefore the results may not be representative with regard to other health care organizations.

Practice implications. The study findings highlight the importance of training all stakeholders together whenever new patient engagement initiatives are implemented. As Gallivan and colleagues have stated, it is important to define exactly what is meant by patient engagement and to establish clearly the initiative's overall goals and specific objectives, as well as the roles and responsibilities of everyone involved.[40] By working together from the beginning, health care providers and patients can learn a common patient engagement language and develop their respective roles, and the outcome will more likely be successful.

CONCLUSION

A change of culture is needed within the health care system to ensure that patients and providers are viewed as equal partners, and that patients' opinions are taken into consideration. Our findings indicate that this TCAB initiative, which engaged patients as partners in care redesign, represents a good strategy for promoting such change at the facility level. ▼

Perhaps the most important facilitating factor in including patients on care redesign teams is for *all* those involved to believe that their participation is crucial to improving the design and delivery of services.

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