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Research

Patient and family engagement: Bridging together interprofessional practice and patient- and family-centred care

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Abstract
Patient and family engagement as part of the health care team is increasingly recommended to meet the objective of providing safer and more coordinated care, as well as enhancing patient satisfaction. This project explores both health care professionals' and patients and families' experiences with patient- and family-centred care (PFCC) and interprofessional practice (IPP). Data were collected through individual interviews with 29 health care professionals and 17 patients and families on medicine and pediatrics at a tertiary care teaching hospital. Inductive coding and thematic analysis outcomes are presented using qualitative description. We used communicative action theory to interpret the gap that emerges in our findings between the ideals and practice of IPP and PFCC. Our findings reveal that strategic action takes place far more often than communicative action. The domination of communication by health care professionals, among other systemic factors in health care, contributes to the marginalized status of patients and families in the health care team instead of being at the centre, and them being informed instead of being truly engaged. The lived experiences of patients and families are overshadowed by the needs of the health care system. Patient and family engagement has the potential to support the implementation of PFCC and IPP in health care delivery. Communicative action theory could be used as a theoretical framework for further research and evaluation of patient and family engagement.

Keywords
Patient experience, patient engagement, workforce engagement, patient and family centred care

Introduction

The Institute for Health Improvement's (IHI) quadruple aims of better experience of care, population health per capita cost, and improving the work life of health care professionals, have become the outcome measures defining health care systems' transformation.[1] Components of health care intended to facilitate transformation include interprofessional team care, patient engagement and collaborative practice as means of providing relational care.[2,3]

Increasing prevalence of chronic multisystem disease requires a transition to health care as a co-produced service, not as a product or a task.[4] Co-produced health care is "composed of a relationship and an action," inclusive of patients' circumstances and lived experiences.[4] Co-production of health care acknowledges the collaborative working relationship between health care professionals, and patients and family caregivers who "develop a shared understanding of the problem and generate a mutually acceptable evaluation and management plan".[2] This shared understanding enables a focus on the individuals and their unique contexts or circumstances and not only on the disease.[3]

The theory of communicative action was developed by Habermas[5,6] and can be applied to describe the aspiration for a collaborative working relationship between health care professionals, and patients and families. Habermas's[5,6] theory centers on the distinctions between communicative and strategic action as well as the lived experience and the system. Communicative action emphasizes a preparedness to harmonize plans of action through common knowledge, mutual understanding, and respect for difference. As Habermas[5] phrased it, "The actors seek to reach an understanding about the action situation and their plans of action in order to coordinate their actions by way of agreement". Strategic action, on the other hand, emphasizes effect. A claim to power is made when verbal articulation (speech) produces a discernible effect. According to Greenhalgh and Scambler,[7] "Strategic action is oriented to success rather than to understanding". Habermas's[6] theory of order (individual lived experiences and the system being two types of social order) is also closely related to his conception of action. According to Habermas,[6] lived experiences are contextually grounded

while the system emphasizes ordered patterns or structures. For communicative action to occur, decisions have to be rooted in the participants' lived experiences that unfold in the everyday world.[8]

IPP and PFCC are often discussed in the literature as discrete concepts, yet both define collaborative care as a common goal. Reeves et al.[3] defined IPP as "a type of work which involves different health and/or social professions who share a team identity and work closely together in an integrated and interdependent manner to solve problems and deliver services". PFCC was defined as the following[3]: "An approach to care delivery which advocates that patients and their relatives are located at the centre of the care-giving process". Three core themes of PFCC identified in the literature are patient participation and involvement, relationship between the patient and health care professional, and context in which health care is delivered, with the goal of providing a meaningful and valuable interaction to the patient.[9]

Patient and family engagement was implemented in health care to address the gap created by 'professionalization' of IPP, implicit in its definitions and concepts.[3] The merging of interprofessional practice and PFCC through patient and family engagement provides the means for delivering co-produced health care.[2,4] The objective of our research was to explore if there is a gap in co-produced care between health care professionals' delivery of care and patients'/families' experiences of care in an acute care setting from the theoretical perspective of Habermas's communicative action theory.

Methods

Research design and setting

Health care professionals, and patients and families were the two groups of interview participants. The interview guides were strategically designed for comparative analysis. We wanted to unwrap the relationship between three important evolving concepts in health care systems: IPP, PFCC, and patient and family engagement as defined by co-production. The first half of the questions focused on PFCC, while the second half brought in the concept of IPP and explored how patient and family engagement could be facilitated to support IPP and PFCC.

The study was undertaken at the Royal University Hospital, Saskatoon, Saskatchewan, Canada, a tertiary referral centre including adult internal medicine and pediatrics. The acute care medicine and pediatric units have both been proactively developing interprofessional teamwork with a focus on rounds.[10] On the acute care medicine unit, interprofessional rounds are daily 'bullet' rounds with members of the health care professions engaging in discussion of ongoing care plans. Acute care pediatrics implemented interprofessional bedside rounds, inclusive of patients and families.

Data collection and analysis

The recruitment of health care professionals was done by the principal investigator via email. Twenty-nine health care providers were interviewed, fourteen from acute care medicine, thirteen from acute care pediatrics, and two who worked on both units. Registered Nursing, Occupational Therapy, Physical Therapy, Social Work, Pharmacy, Registered Dieticians, Speech Language Pathology, Client Care Coordinators, Spiritual Care Providers, and Physicians were interviewed. The recruitment of patients and families was done by the nurse coordinators on both wards. Eleven patients and two family members were interviewed on acute care medicine. On the pediatrics ward, four parents participated in the interviews on behalf of their children who were patients. All interviews took place between November 2015 and July 2016. The numbers of participants from the two groups based on different characteristics are summarized in Table 1 and 2.

After transcribing all the interviews, we utilized inductive thematic analysis and qualitative description for our study. Descriptive and in vivo coding[11] were used to analyze the transcripts. Codes were then categorized by theme which we operationalized to mean an overarching concept to which the participants spoke.[12] Themes that appeared frequently and with greater narrative elaboration in the transcripts were identified and are the focus of this paper. As qualitative descriptive studies provide a comprehensive summary of events in everyday realities and offer "an accurate accounting of the meanings participants attributed to those events",[13] the combined methods of thematic analysis and qualitative description allow us to theorize from the data but also provide rich description. The processes of data interpretation were also informed by the theoretical understanding and concepts of Habermas's communicative action theory (specifically the distinction between communicative and strategic action, and the system and the lifeworld).

This project was approved by the University of Saskatchewan Behavioural Research Ethics Board (Beh# 15-215).

Results

In this section, we compare communicative and strategic action in health care. Interprofessional rounds provide a mechanism for team-based discussion for health care professionals. The perception of the health care team in the intent of interprofessional rounds corresponded to the characteristics of communicative action. However, the described lived experiences of the patients and families revealed that they encountered strategic action during their

Table 1. Participants of Health Care Professionals broken down by Professions and Wards

Professions/Wards	Medicine	Pediatrics	Hospital
Doctors	1	2	0
Registered Nurse	5	3	0
Occupational Therapists	2	1	0
Physical Therapists	0	2	0
Pharmacists	1	3	0
Social Workers	2	1	0
Dietitians	1	0	1
Speech Language Pathologists	1	1	0
Client Care Coordinator	1	0	0
Spiritual Care Provider	0	0	1

Table 2. Participants of Patients and Families Broken down by Identities and Wards

Identities/Wards	Medicine	Pediatrics
Patients	11	0
Families	2	4

hospital stay. The difference between being informed and being engaged, and the conflicts between system goals and the goals of patients and families were emphasized by participants. Co-production was proposed as a framework for meaningful engagement of patients and families.

Interprofessional Rounds: "They will do things out there and come in after…they are all like a bunch of eyeballs"

Interprofessional rounds are perceived as a valuable mechanism for not only IPP but also PFCC because they provide opportunities for conversations and decision-making among and between health care professionals and patients. The bullet rounds in medicine and bedside rounds in pediatrics, according to most, if not all health care professionals, could enhance the care provided to patients through focused communication among the health care providers. According to one health care professional:

> I think the involvement of having bullet rounds definitely helps with meeting each day in order to get the best care for the patient and it is nice to be able to talk to everyone on the team every day… (Health care professional, Medicine)

Some patients and families perceived they had choice:

> They put me on different medications, and they have given me a choice – explaining the pros and cons. They let me think about what I feel would be right for me and they have given their opinions…I can make the final decision… (Patient, Medicine)

Some health care professionals in pediatrics have concerns that not enough patients and families are given the opportunity to participate in interprofessional rounds. One professional in pediatrics discussed how patients are selected for interprofessional rounds:

> Usually, the choices are made based on the most complex patients that would benefit most from having the entire team there to plan with the patient what the day will look like and what the next step will be going forward… We huddle together as a team and decide who would best benefit from the time we have. (Health care professional, Pediatrics)

In addition to the concern that decisions on which patients can be engaged are made by the health care team, many health care professionals in medicine are worried that patients and families are not involved in rounds at all, because the team talks outside the patients' room. They voiced the concern that rounds were for the team but not

for the patients or families. One professional made a distinction between rounds and team or family meetings:

> The bullet round is good but then the family and the patients are not involved in that conversation. Often it will be the doctors who will then pass on what the team talked about… What we call a team meeting or a family meeting, [is] when can we actually bring the whole team together around the patient and the family to talk about their goals and how they line up with our plan of care. I think that is probably the best example of patient-centred care because we have seen it happen where our plan of care completely changes after those meetings once we have a better understanding of what our patients and families are hoping for. (Health care professional, Medicine)

Even in the perceived context of more engaged rounds, the plan of care is decided prior to family meetings, and not developed in discussion with patients and families. Patients and families expressed the same disconnect from the process of interprofessional rounds, during which health care professionals 'are out there' and 'we are in here' and not a part of the dialogue, articulating the absence of communicative action in their hospital experiences. The following example demonstrates that patients and families felt isolated even when physically surrounded by a group of health care professionals trying to provide the best care:

> I can see that they are out there discussing everything, but we are in here. They will do things out there and come in after and then they are all like a bunch of eyeballs and one doctor is doing all the talking so how is that being part of the team? It makes us uncomfortable – that part where they are all hovering and just one doctor talking. (Family, Pediatrics)

Being informed vs being engaged: "I wasn't asked what my goals of care were, they just told me their intent."

Most health care professionals perceived that they were doing their best and were moving the care provided in the right direction by keeping patients and families informed about what is happening. However, a patient's comment – "No, I don't feel like my concerns are at the centre of what happens to me in hospital" articulated a different lived experience. When referring to PFCC or patient engagement, most health care professionals jumped right into a discussion of informed consent and shared decision-making. Providing information is task-oriented, with success being defined as the giving of information. Patients being informed is perceived, by many health care professionals, as patient engagement. One health care provider explained how information is provided in hospital:

> It is supported in that people – patients and family, are given the information about their health care issues and the health care professional provides answers to questions that they have. I think we make ourselves available and answer as best as we can so that they arrive at the decision that is best for them. (Health care professional, Hospital)

However, disagreement still exists among professionals with regards to whether the teams are fully informing patients and families, and what the outcome should be – to meet the needs of the individual patients or achieve the task-oriented goals of the acute care system, namely discharge or transfer to another health care setting. This concern is illustrated in the following example:

> If the patient or family is thinking a different way, I wouldn't say I persuade them. I think I try to make sure that they have all the information to make an informed decision and then they make the decision that is right for them and their family. Sometimes I do not think we do a very good job of explaining why we would think this is a particularly good choice and families may not understand that. (Health care professional, Pediatrics)

One patient echoed this feeling of frustration:

> They are not showing me a picture, they are making me paint by number – that is what I am seeing it as and I don't have the colours to paint it, so I am not seeing it – it's just a blank page. (Patient, Medicine)

Our data revealed that, for patients and families, there is a big difference between being informed and being engaged. It seems the health care system and professionals are getting better at informing patients and families, and including them in decision-making; however, the more relational step, in which patients are actively engaged, is still missing in current practice. Health care professionals dominate the communication – the language, the concepts, what is discussed, when it happens, and how long it lasts. The conversation focus is on 'us' and 'them,' but not a relational 'we,' which demonstrates strategic communication. Action language utilized by health care professionals is unidirectional, as they provide information and educate, but do not describe the receiving or exchange of information. Even though this following example came from the interview with one of the health care professionals, it perfectly revealed the difference between being informed and being engaged:

> …if you sort of say this is what I want to do, and this is what the members want to do and what do

> you think – then I do not think it is giving them an equal voice… I like to say I think we should start with them because they are the most important member of the team, so start with what they think is going on and what their questions or concerns are at the beginning before we kind of launch into what we think should happen. I think the key is that they have to feel safe to participate – like they are not going to be judged and that they have the understanding and the knowledge to be able to participate and feel like they are a valid voice. (Health care professional, Pediatrics)

Health care professionals describe what 'should' be their approach for engaging patients but describe strategic action in their actual approach to care.

The lived experience by patients and families is one of uncertainty and hierarchy. In contrast to health care professionals' emphasis on systemic factors, and strategic communication, patients and families emphasized personal experiences. For example, one family reflected on the interaction with health care professionals:

> At first, I wasn't comfortable asking a lot of questions. I was not comfortable because sometimes I couldn't understand what they were talking about. I felt kind of stupid. I got her father to ask the questions for me but finally I asked the questions myself. I am comfortable now with the doctors and nurses. (Family, Pediatrics)

Due to patients and families' unfamiliarity with how the system works, the existence of hierarchy within the health care system, and lack of communication or miscommunication, patients and families are not invited to be engaged in their care.

Patients and families described a lack of respect in their interaction with health care professionals, which was a repeated theme in their interviews. The following was one of the examples:

> Patients don't like the hospital because they don't feel like they get respect from anybody. They are just another number on a spread sheet. (Patient, Medicine)

The hierarchy or power differential results in fear and uncertainty to speak, decreasing satisfaction with the health care experience.

Engagement happens when either the patients in medicine or families (parents) in pediatrics actively seek opportunities, often with the felt need of a confrontational approach to participate in co-produced health care. One patient who is familiar with the health care system commented on her unique background and knowledge, and how things could easily be very different for other patients:

> I am a very outspoken person. I have no problem ruffling feathers if I need to do so but I would guess the vast majority of people are not or do not know the system and so it would just be really nice to not have to expect that other patients that are quiet are going to sit and suffer because they're not brave enough to say anything, or they do not think it is their place. It would just be nice to have that automatic inclusion so that patients can feel like, yeah, I helped get myself better. (Patient, Medicine)

Two parents in pediatrics attributed the timely recovery of their child partly to the fact that they were able to persistently voice their wishes to be a part of the rounds and decision-makings every step of the way:

> We have been really assertive telling our team that we want to be part of rounds… I do not know what the procedures are for including parents or asking if they want to be part of it, we just kind of inserted ourselves. Not really asking if we could be there, just being there. (Family, Pediatrics)

The task-based hierarchical health care system, and the felt need of patients and families to advocate for themselves to overcome strategic communication demonstrate that the health care system and health care professionals should define a role for patients and families as equal members of the health care team.

System vs lived experience: "When [I am] hurting, I like to be left alone and people are poking and prodding at me."

Health care professionals are inclined to emphasize systemic factors when identifying challenges and obstacles to IPP, PFCC, and patient engagement. Time constraints and understaffing are two interrelated and most discussed systemic factors. Some health care professionals advocated to have protocols (either a leader who is in charge of the rounds or a checklist) in place to make sure that every profession and care provider is on the same page with expectations that rounds are embedded in the hospital setting as a systemic factor to support patient care. Protocols, however, would emphasize the task-based focus of rounds, adding to the challenge of communicative action as a method mechanism of patient engagement. One health care professional described a perfect model she could imagine:

> It would be having enough staff for every team, so say on pediatrics [which has two interprofessional teams], enough of staff to have one person at least dedicated to that team from each different

> profession and it would involve rounding on every patient as a team with caregiver or patient present in rounds and the decisions being made as a team with the family. (Health care professional, Pediatrics)

Patients and families themselves also acknowledged the concern regarding understaffing:

> They need more time for the nurses to actually talk to the patients. They are just rushed. I know they do as much as they can but just a little more time would be nice. I would like to ask more questions. (Patient, Medicine)

However, perceived sufficient staffing would not necessarily result in patient engagement unless there is a shift in communication from strategic (task-oriented) to communicative action (mutual understanding-oriented).

The lived experience of patients, families and caregivers has a more longitudinal focus, with an acute care stay considered an episodic event in a continuum of care. Patients and families have the contextual knowledge of their illness, including goals and values of care, and their physical state. One patient explained the importance of this lifeworld:

> The doctors and nurses are listening to what your symptoms are and what you are feeling and what is going on according to what you are experiencing, and I find they take a lot of input from you which I think is wise because you know your body and if you have lived with an illness, you know things the doctors can't know. (Patient, Medicine)

However, patients did not always feel their experiences with their own illness were acknowledged, nor did they contribute to their recovery. The following was one of the examples that demonstrated this:

> I know my body best, but if I'm not included in their discussions, they have no idea what I am feeling…if they are doing their multidisciplinary rounds out there, but I certainly don't feel like part of the team or part of my own care at all, until I started pushing for it. (Patient, Medicine)

The system needs flexibility to accommodate diversity in patients' lived experience, necessitating communicative action from the beginning of their hospital stay. Incorporating the individual contexts of both health care professionals, and patients and families, into conversations of mutual understanding, is necessary for co-produced care.

Coproduction: "When it does come together…it's pretty amazing and a lot of fun to be a part of."

Co-production is a relational approach to providing care, dependent on communicative action, namely a dialogue or exchange of information between health care professionals and patients and families with the goal of mutual understanding and shared plans of care. There is acknowledgement of the dominance of system pressures by the health care professionals and the barriers this creates for dialogue and shared decision-making. According to one health care professional:

> It's been an evolution over 18 years. Before, decisions were made behind closed doors. Now there is involvement of patients and families. That evolution has not been easy. (Health care professional, Medicine)

There is recognition of what interprofessional rounds could and should be with co-produced care:

> When it does come together, even for just a single patient and we have an interdisciplinary team including the patient consistently for a few days leading up to discharge for example, things go very, very smoothly…things kind of align and the team functions well. It's pretty amazing and a lot of fun to be part of. (Health care professional, Medicine)

Respect and equal voice of participants involved are necessary components of interaction for co-production to occur, so is the system that recognizes the role of patients and families and actively engages them.

Discussion

Engaging patients and families to be a part of the health care team through bridging the purposes of IPP and PFCC and transitioning to co-produced care, define the goal health care professionals aspire to achieve. The reality experienced by not only professionals, but also patients and families in an acute care setting has glimpses of these ideals, which rarely occurred within our study. The most common observation of lived experiences was that of a traditional care model, in which "patients and families tend to be rhetorically included but practically excluded" from decision making.[14,15]

In the current health care practice, the relationship preconditions that facilitate communicative action, theoretical ideals of mutuality, trust, power-sharing and sincere exchange of information, and acknowledgement of the lived experience, are rarely met.[7] "Lack of trust, intense pressure of time, mismatch of agenda (biomedical vs. patient experience), firm expectations of a specific outcome and profound power imbalances all promote strategic action (i.e., speech that seeks consciously or unconsciously to manipulate outcome) rather than communicative actions (sincere efforts to achieve

understanding and reach consensus)."[7] The system's needs override patients' unique needs, with minimal evidence to suggest a shift from professional to patient centric model of care, as observed in this study.[3,4]

Co-produced health care can only be achieved through communicative action.[3,9,15,16] Communicative action provides opportunities for information exchange, mutual understanding and agreement, and relationship building, which should be based on patients' lived experiences and unique needs.[17] As the extent of mutual understanding within the health care team increases, the facilitation of decision-making becomes more equally shared among team members.[18] By understanding each other's motives for care, health care professionals and patients and families acquire common knowledge "enabling power sharing, joint decision making and client autonomy".[16] There is recognition of this necessity; however, it is and will be a challenging transition to co-produced care to better meet patients' needs and expectations that requires both individual and systemic factors.[19] When collaborative co-produced care occurs, participants "recognize that something better is happening".[15] This 'something better' is a relational approach to care with levelling of hierarchy and resulting exchange of information, understanding and respect through dialogue, a description of communicative action. In co-produced care, care is "better and easier."[15]

Currently, evidence of co-production is defined by health care professionals' perceptions of their own collaborative performances.[3] Evaluation strategies that respect and meaningfully engage the patients and their families in the planning and delivery of services are necessary for a transition to co-produced patient and family- centered care. As supported by this study, the best way to measure the success of health care delivery is an evaluation of the lived experiences of patients and families.[9] Families are an unrecognized member of the care team who not only provide care but who also have care needs in their role as caregiver, and their own unique role in co-production and its evaluation.[20] Patient and family education, staff's professional development, and institutional evaluation and measurement are essentials to implementing and sustaining co-produced care.[4] Utilizing Habermas' communicative action theory as a theoretical framework could potentially be beneficial for further evaluation and research in health care and patient experiences.

Concluding Comments

Currently, systemic factors and resulting strategic actions create provider-centric health care. Traditional care occurs when decisions are made strategically on behalf of patients, directed by systemic factors, with only the perception of patient and family engagement.[7,15] Co-produced care makes decisions with patients and families through communicative action or mutual understanding embedded in the context of lived patient experiences.[15] Habermas' communicative action theory provides the theoretical framework and language to anchor practice and evaluation for transforming health care based on systemic tasks to the needs and goals of patients and families.

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