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Transforming the experience of illness into action – patient and spouses experiences of involvement in a patient and family advisory council

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ABSTRACT

Objective

The objective was to explore patients' and spouses' perception and attitudes towards participating in a patient and family advisory council.

Methods

A qualitative study with interviews conducted within a phenomenological-hermeneutical frame, inspired by Ricoeur were conducted with current and former participants (patients and/or spouses) of a patient and family advisory council in Denmark.

Results

In total, 16 participants were interviewed (12 former patients/four spouses) with a mean age of 68 (range 49-79) and 44% women. After the analysis, perceptions and attitudes towards participating in a patient advisory council emerged in four themes; *"Payback"*, *"A personal invitation"*, *"A safe and equal atmosphere"*, and *"Sharing, caring, and healing"*.

Conclusion

Participants of an advisory council express a need for "paying it back" to the health care system. When being part of the advisory council, the participants expressed feeling a genuine engagement and interest from the health-care professionals – leading to a feeling of being equal and taken seriously. The advisory council increased the process of recovery by sharing narratives with peers.

Practical value

Experiences of being part of an advisory council lead to an understanding of "why" former patients and spouses participate. This knowledge can help others to recruit members.

1. INTRODUCTION

Patient engagement, as a growing concept within health-care, can be defined as an active partnership between patients and health-care professionals and as actively involving patients in treatment and care [1]. Currently, patient engagement is highly prioritised within the health-care system and is typically performed at an individual level, an organisational level – or a level of governance and policymaking [1-3].

At an organisational level, patient engagement includes patient surveys and involvement in hospital safety- and quality improvements [4]. Thus, the perspective of the patient at an organisational level includes involvement in decision-making processes, developing initiatives and evaluation of provided health-care [5]. Similarly, patient and family advisory councils can be perceived as patient engagement at an organisational level [6]. Patient and family advisory councils include both patients, family caregivers and health-care professionals. Although the actual structure and concept of a patient and family advisory council can vary, the councils often meet regularly to obtain the perspective of the patients and family caregivers on different topics. Patient and family advisory councils help identify practice improvement priorities and support the health-care staff and leaders in quality improvement. As both patients and family caregivers possess essential knowledge and personal experiences about the health-care system, this type of patient engagement is of great importance for health-care professionals [4].

Although several studies have investigated the use of public involvement in the health-care system in a broader perspective [3, 7-9], only a few have investigated the effect of an organisational patient (and family) advisory councils on overall outcomes, including the delivery of care [4, 10]. Findings from a recent systematic review demonstrate how patient advisory councils may be beneficial to both the individual patient advisors as well as the health-care system [4]. The review included several case-studies, whereas evidence from prospective experimental trials is lacking [4]. Similarly, specific studies investigating the perspectives of patients and family caregivers on participating in advisory councils are sparse [11, 12]. As initiating and maintaining advisory councils are a continuous task, more understanding of the perspective of patient and family caregivers is needed. This knowledge might help inform clinicians about factors to be aware of when organising patient and family advisory councils.

Thus, this study aims to explore patients' and spouses' perception and attitudes towards participating in a patient and family advisory council.

2. METHOD

2.1 Design

This exploratory qualitative study was underpinned by a phenomenological-hermeneutical approach based on the French philosopher Ricoeur creating an epistemological stance for exploring first-person accounts of the experience of participation in a patient and family advisory council [13, 14]. This approach offers a framework where participant experiences can be interpreted, and a comprehensive understanding can be developed in a process going from experiences before they are formulated as a spoken narrative to formulating a narrative, and to the actual comprehension stage where the text is interpreted [14].

2.2 The patient and family advisory council

The patient and family advisory council was initiated in October 2014 at the Department of Cardiothoracic and Vascular Surgery, Odense University Hospital in Odense, Denmark. The advisory council included former patients and/or their spouses and health-care professionals (managers and clinical staff). Participants of the patient advisory council were invited to participate in a two-hour afternoon-meeting three-four times per year. At each meeting, the overall aim was to develop a more patient-centred clinical practice by incorporating knowledge from the former patients and spouses into quality improvement initiatives within the Department. Areas to be discussed included written patient material (paper-based and electronic solutions), new initiatives, results of research projects and future organisational challenges, among other topics.

2.3 Participants and data collection

All current and former participants of the patient and family advisory council (former patients and/or spouses) were eligible for inclusion in the study, and were asked to participate in two ways: current members

of the advisory council were invited during a meeting in the council, and former members were approached by e-mail or by telephone. Data collection was performed from April to October 2019.

A total of 13 patients and four spouses had participated in the advisory council, but one former patient had died. Thus, a total of 12 patients and four spouses agreed to and were included in the study.

2.4 The interviews

The interviews were conducted individually with former patients or in conjunction with their spouse based on the participant's preference. Structure of the interviews was inspired by Kvale and Brinkman, meaning, that the interviews were performed based on an interview guide consisting of open-ended questions to allow for participants' reflections and narratives about phenomena and experiences throughout the interviews [15]. Each interview began with a broad opening question, such as; "Could you please tell me about your experiences from participating in the patient and family advisory council?" Supplementary Table 1 lists the interview questions. Throughout the interviews, the participants were encouraged to narrate their experiences of participating in the advisory council.

The interviews were conducted separately by three different research assistants. Interviews were performed in the home of the participants or at the hospital, as preferred by the participants. The duration of the interviews ranged from 25 to 57 minutes, and all interviews were audio-recorded and transcribed verbatim.

2.5 Data analysis

According to Ricoeur, embedded in a language is always a meaning that extends beyond the direct linguistic expression [13, 14, 16]. As such, language, including texts, contains connotations that can only be approached through a process of interpretation. The focus of interpretation is not the text, the transcripts, in itself, but the issues that are at stake in the text. Based on Ricoeur, the interpretation process involves different layers of meaning understood as an endless spiral involving three levels; a naive search for the

overarching meaning which the text seeks to convey, a linguistically oriented structural analysis, and an in-depth, comprehensive interpretation [13].

In the naive interpretation, reading and re-reading of the narratives took place to gain a first understanding of what the texts are about. It is a surface interpretation that Ricoeur calls a naive grasp of the meaning of the text as a whole. This first interpretation helps to provide an overview of the narratives. The structural analysis provides an insight into the structure of the text. Specifying the structure gives the text an objective content. Words and sentences are extracted, which point towards an issue or a theme that recurs throughout the text. It is a movement between quotes and the interpreted meaning, dividing the interview texts into units of meaning comprising sentences or paragraphs, which was then condensed and compared across the texts. Similar units of meaning were clustered and separated into sub-themes and then main themes. As such, the structural analysis was carried out at three levels involving what the text said (quotes); what the text spoke about (meaning); and the texts structured into themes (interpretation). The function of the structural analysis is to enable a more in-depth interpretation, thereby exceeding the naive understanding [13]. The comprehensive interpretation continues with an in-depth interpretation and discussion of the themes identified in the structural analysis. Where structural analysis is solely aimed at a closed system of symbols, the comprehensive interpretation is aimed at understanding the meaning and range of the text's statements. Thus, the interpretive understanding elaborates a deeper understanding of the life-world phenomena that have been included as traces in the participants' narratives. The analysis and interpretation are illustrated in Figure 1.

2.6 Ethical considerations

The study was approved by the Danish Data Protection Agency (19/15326) and conforms with the principles outlined in the Declaration of Helsinki [17]. The Regional Ethics Committee was notified about the study (ref no. 20192000-61), but due to Danish legislation, interview-based studies do not need ethical approval.

All participants signed an informed consent after preliminary verbal acceptance during a council meeting or by telephone.

3. FINDINGS

The patients' and spouses' perceptions and attitudes towards participating in a patient and family advisory council are revealed in four themes; *"Payback"*, *"A personal invitation"*, *"A safe and equal atmosphere"*, and *"Sharing, caring, and healing"*. These themes are described in the following section and exemplified by the use of quotations from the transcribed interviews.

3.1 Payback

A prominent issue for agreeing to participate in the advisory council was yearning for paying back for the treatment and care received by the participants. Both patients and spouses expressed finding themselves in a vulnerable period in life where the actual treatment and procedures, as well as the health-care professionals' approach and competences, were paramount for the possibilities of continuing living. Through a life-threatening illness, the participants' experience of being cured, relieved and cared for, resulted in wanting to pay it back: *"I'm so grateful for you – you've cured me, so I owe you a lot"* (Patient participant 1). It was not enough for the participants to thank the health-care professionals, they needed to *do* something, and being part of the advisory council met this desire of "doing". Thus, the council was seen as a welcoming opportunity to engage in meaningful work and demonstrate their feelings of gratitude: *"I feel like I owe you tremendously, but when I tell you that I am grateful, you respond that you are just doing your job. When I can't give you anything but a "thank you", then I might be able to pay you back like this [by participating in the advisory council]"* (Patient participant 4).

A component of paying back also included a fundamental attitude towards helping future patients.

Perceptions of being able to contribute with knowledge and experiences so that other patients are treated in the best way possible were crucial for the participants.

3.2 A personal invitation

All the participants narrated how they had all received a personal invitation from the health-care professionals when asked to be part of the council. They believed that written posts about the group could create uncertainty and would not necessarily lead someone to volunteer. Being invited in person created a feeling of being “handpicked”, and that one’s experiences and knowledge were worth something. It meant that the participant felt valued as someone who could offer important insights and contribute to the health-care system. However, the timing of inviting participants in the council was crucial. Participants described how the period after hospitalisation was stressful with physical consequences and emotional reactions, taking up most of the time in everyday life. Ensuring that participant recruitment was performed sensitively was essential to avoid additional distress. The patients and spouses wished to be able to give input to the advisory council, which were not possible immediately after discharge. When inappropriately timed, the participants feared that their own needs and problems would have overshadowed their otherwise significant contributions:” *In the period following the surgery you’re emotional, so you need some time before participating in something like this [the advisory council], to be able to see and properly discuss things. The period following the surgery is difficult. It’s really about being able to contribute and not sitting there with watery eyes being sad – that’s not the point of being there*” (Patient participant 9).

Similarly, the spouses were recognised as important team players in the group. They were the ones who had been alongside the patient throughout the illness and had been able to observe, feel and reflect on the health-care system. Thus, both patients and spouses experienced how spouses contribute with different and significant perspectives to the council.

3.3 A safe and equal atmosphere

The atmosphere in the advisory council was perceived as being an equal and trustful environment with a genuine interest and a listening approach among the group. The atmosphere meant that the participants felt safe and provided an opportunity for everyone to participate in discussions. It also provided participants with

a feeling that their contribution to the conversation was taken seriously;” *I felt assured that I could say whatever I wanted. That was definitely due to your [the health-care professionals] way of being – you were openminded, leading to us [patients and spouses] being too*” (Patient participant 10). This was perceived as a specific way of patient engagement.

The construct of patients, spouses and health-care professionals in the council was experienced as a particular strength which forces the participants to listen carefully and respectfully to each other. The importance of health-care professionals wishing to prioritise the meetings created a sense of seriousness of patient engagement and genuine interest. Besides, participating leaders were perceived as being crucial to the feeling of “the system” to listen – instead of “just” the individual nurse or physician. The experience of the leaders listening gave the participants a sincere belief of influencing the system directly, which otherwise did not always seem possible.

Another important aspect adding to the equal and professional atmosphere in the council was the planning and managing of the meetings. Participants pointed out the importance of receiving an agenda before the meetings and minutes afterwards. This provided a feeling of being an equal partner by adding their knowledge of the health-care system to improve care and treatment. It provided them with confidence that their input and recommendations would be considered when changing and developing clinical practice. Thus, being part of the advisory council created a unique opportunity to gain knowledge about the logic of the health-care system and its organisation, which seemed otherwise regarded to the system itself and hidden away from “common man”.

3.4 Sharing, caring, and healing

Patients and spouses expressed several personal benefits of participating. Of particular importance was the processing of own illness through the sharing of one’s narrative. In sharing this, both caring and healing aspects were described. Listening to illness narratives of others’ created a community among participants

where one could be affected by the suffering of others while putting into perspective their own story of illness.

Furthermore, recognition of emotions and reactions created feelings of cohesion in the group: *"There's a sense of coherence in the council..." (Patient 7); "It was nice to be around someone, who has had some of the same experiences – to be reassured that you're not the only one feeling like that" (Spouse 1)*. Putting one's illness trajectory into perspective helped to confirm they were not alone. The participants described how it could be difficult for their families and social network to understand what they had been through, whereas they were more comfortable to share and to be understood in the group. Similarly, the couples who participated in the advisory council together received a special opportunity to share and verbalise reactions, emotions and worries together. They described the challenges they faced sharing their experiences; however, talking and participating within the group setting facilitated the illness to be a shared experience.

The illness and subsequent challenges in daily life became more comfortable to manage when shared with others in a similar situation: *"It gives you something, to mentally put it somewhere [the illness trajectory]. When you have talked about it the first time, then it's not as difficult to talk about the next time. You deal with some things by talking about it. When you participate in the council, you move on a bit... I wouldn't say that you remove the issues completely, but you find a place to put them"* (Patient participant 9). Although sharing a similar story could have a healing impact, it may also be stressful. The participants narrated this as an ambiguous feeling of wishing to go on with life on one side and the healing impact on the other side. The meetings constantly reminded them of the vulnerability of life and the subsequent exhausting illness trajectory they had been through; nevertheless, the participants stayed in the council as long as they felt they contributed.

4. DISCUSSION AND CONCLUSION

4.1 Discussion

This study is one of the first studies to illuminate how patients and spouses experience participating in a patient and family advisory council. Participants described the inclusion in the council as an opportunity for them to thank and payback to the health-care professionals and the system for treating them when they were most in need. The feeling of payback arose from gratitude among the participants in our study. Gratitude, which can be seen as a broader view of life, including taking note of and appreciating the positive aspects of life [18]. Similar to our findings, a recent study exploring perspectives of surviving an out-of-hospital cardiac arrest also highlighted how patients feel gratitude – and emphasised the significance of having an opportunity of expressing this gratitude [19]. Research has demonstrated that gratitude is associated with both emotional and physical well-being and has the potential for promoting positive functioning and psychological strength [20]. As such, the payback approach might be a positive diversion of participation in the patient and family council. On the other hand, Madden and Speed have described how such an attitude can be based on politeness, meaning that insufficient attention may be paid to connections between clinical and public health contexts [21].

A systematic review on patient-, family-, and community advisory councils in health care suggests that strategies for recruitment should be investigated [22]. In our study, a personal invitation to participate in the patient and family council was described to be of particular importance. To receive a personal invitation, provided patients and spouses with a sense of being significant and essential. They felt that they had something consequential and unique to contribute to the council. As no participants volunteered through posters or other advertisements, the participants were invited through the out-patient clinics, rehabilitation and public meetings. This can lead to a discussion of whether the participants are a representative group of patients. In general, it is well known, how representativeness can be a problem in public participants in health-care [3, 9], and although the participants in the council consist of members of different age groups, educational level and genders, engaging a diverse range of patients can be challenging.

During clinical encounters when a patient is admitted to hospital, the relationship between the patient/spouse and health-care professionals are usually not equal in a professional context [23]. This unequal relationship is a product of health-care professionals possessing legitimised, referent, and expert power and patients being reliant on health-care professionals to provide the care and services they need [24, 25]. A challenge in patient and public involvement in health initiatives has been focused on power inequalities [26]. The atmosphere experienced by participants in the current council was, however, described as safe and equal originating from values such as dialogic, equal, and a patient-centred approach. As such, the health-care professionals "shared power" is through engaging on equal foot with the participants. Bourdieu's theoretical concept of "habitus" describes a set of learned "dispositions" and inclines individuals to act and react in specific ways. Through different processes, an individual acquires a set of dispositions that becomes natural and embodied. These dispositions generate practices, perceptions, behaviour, and attitudes which reflect the social conditions within which they were acquired and affected the relationships [24]. Habitus can change over time with exposure to specific social fields and is thus not static or permanent. The council was a social field and a site of negotiation in which participants, health-care professionals, patients and spouses sought to maintain or alter the distribution of different forms of capital which was possible due to the willingness of shared power. These findings have previously been demonstrated in a study of patient and family perspectives on engagement in health-care quality improvement initiatives [27]. This demonstrated participants' new insights into the structure and operations of the system, affirmation of their right to advocate and recognition of the potential to claim spaces of power as consumers [27].

According to Frank [28], an ill person is "wounded", and the healing process should start by allowing the patient to tell and share his/her story. Serious illness, according to Frank, is a loss of the "destination and map" which previously guided a person's life, and ill persons must learn to think differently. Hearing themselves telling stories about their illness and life situation is a step towards altering their thinking. Other research has reported anecdotal benefits to patient advisors [29], and our study furthermore illuminated how the shared community among participants was significant in their healing processes. Being a patient in a vulnerable and life-threatening situation tied them together. By sharing their own story of illness and

listening to others' stories, the participants became equipped with a language of what they had lived through in the vulnerable period of illness. Other studies have demonstrated how peer support and sharing experiences of illness have a significant impact on the individual's illness transition experiences and orientation into a new life situation [30, 31].

This study has illuminated the patient and spouse perspective on the importance of participating in a patient and family advisory council at a tertiary hospital in Denmark. In general, patients tend to believe having a patient and family council is of great importance, as patients in hospital boards increase their overall trust with the health-care system [10]. However, initiating and maintaining patient and family advisory councils requires a genuine effort from the health-care staff and thus, retaining participants onboard is a continuous task. Additionally, the maintenance of such a process over time has been reported to be difficult [32].

Therefore, the rigorous perspectives of participants in our study are needed to support the process. Initiating and maintaining a patient and family advisory council requires a commitment from the staff and clinics and hospital leaders may be resistant to investing in patient engagement without clear evidence to support their benefit [4]. A willingness to invest and to share power with patients and spouses as recommended in our study can be a practical tool for meeting requirements of patient-centred care and patient engagement in health-care.

4.1.1 Methodological reflections

The researchers acknowledge how the sample of participants might not reflect all types of patients as not all patients and their families volunteer to participate in advisory councils even though it is a critical part of patient-centered care [33, 34]. Thereby, perspectives from a broader patient population may not be engaged as representatives in quality improvement initiatives in our study. Participants from a study exploring patient engagement through patient and family advisory councils report a widespread agreement that members of such councils commonly have great communication skills, are good listeners, open-minded, and have compassion. As such, the ideal member should use those skills to advocate for others, with a passion for

helping and being able to speak for others [35]. Through the analysis of transcripts from our study, we believe our participants all demonstrated a passion for helping others despite the benefits for themselves. Additionally, a strength of the sampling strategy for the present study included the complete sample of all possible participants. All former participants agreed to participate in interviews regarding perception and attitudes towards being part of the patient and family advisory council.

Contrary, one surprising aspect throughout the study was the patients' reluctance to criticise the health-care system and health-care professionals. This may be explained by the relationship that emerged in the council with a safe and equal atmosphere and caring environment. The absence of criticism may also be related to the fact that the interviewers also participated in some of the council meetings. Thus, the interviewers were known to some extent to the participants – this may have had an impact on the positive responses. Additionally, the participants might have felt that they owed to participate in interviews. Thus, this is a limitation of the study. An interviewer not known to the participants beforehand would have substantiated the findings.

4.2 Conclusion

After undergoing surgery and being hospitalised due to a severe condition, patients and spouses express a need for “paying it back” to the health-care system by participating in a patient and family advisory council. When being part of the advisory council, the participants expressed feeling a genuine engagement and interest from the health-care professionals. They expressed how this leads to a feeling of being equal and taken seriously, though it cannot be ruled out that power differentials in the advisory council affected what the participants were willing to say. Finally, the advisory council increased the process of recovery by sharing narratives with peers, although it also reminded the participants of a stressful period of life.

4.3 Practice Implications

The study contributes to the experiences of being part of an advisory council, which leads to an understanding of “why” former patients and spouses participate. This knowledge can help others to recruit members by adding information on the need of having a personal, face-to-face invitation and the importance of letting the patients recover before being invited.

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Conflict of interests

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Figure Legends

Figure 1. Illustration of the analysis and interpretation process