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Discussion

Co-design for implementing patient participation in hospital services: A discussion paper

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1. Introduction

Patient participation is increasingly recognized as a key component in healthcare. Patients' experiences and knowledge are considered as complementary and equal in importance to professionals' knowledge [1], both in individual care contexts and in healthcare organization [2,3]. Direct patient participation methods have been proven to lead to patient-centeredness and better care [4], but developing and implementing such methods is often a complex matter [5,6]. The use of the co-design methodology could offer a solution for designing and implementing these complex interventions. "Experience-Based Co-Design" is a specific form of co-design in healthcare. "Experience-based" refers to how patients feel about the used healthcare services and how well they serve their needs. "Co-design" indicates that both patients and healthcare professionals act as designers of the healthcare services. Also, it can be seen as an implementation strategy as it has the potential to counter reluctance within healthcare teams [7]. Overall, EBCD is a rigorous participatory approach that enables both staff and patients to (re)design services together by sharing experiences, identifying priorities, implementing and evaluating improvements in care and service provision [8].

2. Background of EBCD

EBCD has already been used in several countries, in at least 57 projects, and in a variety of settings [9]. It originates from design science and draws on the idea that products and services could be improved by involving the end-user in their design. By combining insights from design science, organizational learning and patient engagement, Bate and Robert [10] transferred this user-centered approach into the healthcare context. Using a range of qualitative methods, the approach seeks to capture and understand how people actually experience a process or service in healthcare. Key moments that shape a person's overall experiences ("touch points") are identified. Patients and hospital staff then jointly set priorities and seek solutions. A full version of EBCD includes eight stages: (1) gathering hospital staff experiences through clinical observations, (2) filmed in-depth narrative- based interviews with patients or families, (3) editing the interviews in a 30-min trigger film, (4) staff feedback event to review themes from staff interviews to identify priorities for improving services, (5) patient feedback event to view the edited film and to identify

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priorities for improving services, (6) joint event bringing staff, patients or families together to share their experiences of a service and identify their shared priorities for improvement, prompted by an edited 30-min trigger film (7) co-design groups of staff, patients or families working on implementing improvements relating to identified priorities, and (8) an evaluation/celebration event [11]. Recently, accelerated versions of EBCD have been designed and tested using video interviews from a national database [12], but the innovative elements of remained the same: patients' active involvement throughout the entire improvement process, including implementation.

3. Methods

We describe three studies to illustrate the fit between co-design and implementing complex healthcare interventions; each study used co-design to (re)design and evaluate a patient participation intervention introduced by the researchers. Applicability of the interventions, based on theoretical knowledge, needed to be discussed with those who would benefit from them or might be harmed by them. Therefore, patients and hospital staff were involved by use of interviews and group meetings. Two important considerations in the evaluation of interventions were desirability and feasibility. Although the three studies used co-design, they varied in terms of scope, length and complexity.

The first study aimed to design and implement the "experts by experience intervention", which involved trained patients in the delivery and evaluation of hospital services [13,14]. Experts by experience were systematically involved to support their peers and provide feedback to hospital staff about the care and its organization. The intervention took place in three settings of a large university hospital in Belgium. In each setting, a full co-design trajectory was performed. Experts by experience were, together with other patients and healthcare staff, involved in the co-design process. Adaptation were made to the original EBCD-version. First, participants were informed about the co-design trajectory by means of a video message. Second, discharged patients (>1year) were also included to provide a broader perspective on healthcare by including patients who had already processed their physical and mental problems. Third, researchers provided literature-based knowledge during the process to equally combine experiential knowledge, practical knowledge and scientific knowledge. Lastly, staff interviews were filmed to treat patients and hospital staff equally. The two latter adaptations are grounded in the responsive evaluation and the empowerment evaluation methodology which served as a framework in our study [15,16]. Reflecting on our approach, the embedding of co-design in the two well-established evaluation frameworks increased mutual understanding and facilitated an open dialogue among stakeholders. To ensure full participation of the experts by experience it was necessary to conduct an extensive co-design trajectory where all aspects of the intervention and its implementation were discussed together (e.g. goals of their engagement, tasks and roles, practical organization, dissemination of the project). However, our approach was costly and time consuming as 43 individual filmed interviews, nine group meetings and nine co-design groups were organized together with four researchers and three moderators.

The second study aimed to develop and implement the Tell-us Cards in eight settings in six hospitals. The Tell-us Card is a tool, which facilitates communication between nurses and patients by inviting patients to write on the Tell-us Card what is important for them concerning hospital discharge. The card offers the possibility to identify patients' preferences and needs to be acted upon by nurses [17–20]. Admitted patients and nurses were selected in each setting to participate in the co-design trajectory to tailor the tool for the local context. Due to the practical nature of the Tell-us cards, the co-design process was comprehensively shortened. Film-editing in the third stage was replaced by using audio fragments from the interviews of both nurses and patients. The sixth, seventh and eighth stage were held together. In our opinion, the co-design approached was supportive in tailoring the intervention and creating acceptance on the ward. However, a more substantial and comprehensive explanation of the intervention to prepare the stakeholders would have been useful. The duration of the shortened trajectory was sufficient.

The third study used the co-design trajectory to design and implement bedside handovers on nursing wards. Bedside handover is a process where the shift-to-shift report between nurses is delivered at the patient's bedside to improve the patient's involvement [21]. The goal was to use bedside handovers [17–19] as new standard in fourteen services in eight hospitals. Admitted patients and nurses were involved to fine-tune the intervention. To reduce length and intensity of the co-design process, adaptations were made to the classic EBCD-trajectory. First, all respondents received an information brochure in combination with verbal explanation. Second, patients were selected on availability (i.e. present on the ward). Third, instead of using an edited film, written quotes from patients were used in the third stage of the co-design trajectory. As the intervention was quite straight-forward, the sixth and seventh stage were merged. Finally, the celebration event was not organized but comprised of a gift in the final session. The adaptions were made from a perspective of cost-effectiveness. Looking back to our co-design trajectories, our approach enabled us to tailor the intervention for both patients and nurses, without overusing the available time resources. Moreover, the interactions with patients were valuable to overcome barriers that were initially reported by nurses. As such, we consider co-design as an appropriate implementation strategy. However, we experienced one difficulty: by using written quotes from patients instead of videos, nurses were confronted with patients' opinions quite late in the trajectory.

Based on observations, recordings and field notes of the 25 co-design trajectories in 15 general and university hospitals in Flanders, two research teams analyzed and triangulated their observations using the five phases of Atkins and Murphy's model of reflection: awareness, describing the situation, analysis of feeling and knowledge, assessment of the relevance of knowledge, identifying and learning. Experienced barriers and enablers were described, analyzed, and translated into nine points of action and recommendations [22].

4. Points of action and recommendations

4.1. Preparation of co-design

Sufficient preparation to ensure patients and staff feel comfortable with the method is highly recommended. Both patients and hospital staff should be prepared for the interviews. Being interviewed is usually a new and exciting experience, especially if interviews are (video-/audio)-recorded. For some participants, this method can even be slightly frightening and prevent patients from speaking freely. To create trust and put participants at ease, we suggest providing patients with a detailed explanation of the trajectory and the purpose of the interviews, not solely on paper but also on film/in person. Preparations and planning are important, but so is 'letting things go', as not everything is controllable. For example, some patients abandoned the project and continuing to pursue these patients is not recommended as it contravenes the principle of patient self-determination, which should be respected in all co-design trajectories.

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