



# Patients' perspectives on care pathways and informed shared decision making in the transition between psychiatric hospitalization and the community

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## Abstract

**Rationale, aims, and objectives:** Patients with mental health problems experience numerous transitions into and out of hospital. This study explores former patients' views of pathways in transition between district psychiatric hospital centres (DPCs) and community mental health services.

**Method:** A descriptive qualitative design was chosen. Three focus group interviews with a total of 10 informants from five different communities were conducted. Interviews were transcribed and analysed thematically where themes describe promoting or inhibitory factors to the transition phase.

**Results:** The informants shared their experiences on issues promoting and preventing successful care pathways in mental health. Four main paired themes were identified: (a) patient participation/activation/empowerment versus paternalism and institutionalization, (b) patient-centred care versus care interpreted as humiliation, (c) interprofessional collaboration or teamwork versus unsafe patient pathways in mental health services, and (d) sustainable integrated care versus fragmented, noncollaborative care.

**Conclusions:** Shared decision making was reported more precisely as *informed* shared decision making. Shared information between all parties involved in care pathways is key.

## KEYWORDS

care pathways, community mental health care, district psychiatric centre, patient-centred care, patient transition, psychiatric services, service user involvement, shared decision making

## 1 | INTRODUCTION

Transition of care is an important topic in health care. This is particularly the case for patients with mental health problems who experience

numerous transitions into and out of hospital. Many such individuals experience multiple hospitalizations for brief periods of time—a phenomenon often referred to as the “revolving door.”<sup>1</sup> Importantly, these patients have diverse preferences for care and face a variety of barriers

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associated with mental health treatment. This context suggests the urgent need for easy access to a range of treatments and providers.<sup>2</sup> The Joint Commission Center for Transforming Health Care (USA) defined transition as the process or period of changing from one state or condition to another and refer to the movement of patients between health care practitioners, settings, and home as their condition and care needs change.<sup>3</sup> There is a growing interest in creating care pathways in mental health to improve the quality of care through enhanced care coordination. Care pathways are understood as interventions for the care management of mental health patients in need of complex health services during a well-defined period of time.<sup>4,5</sup>

Patient activation is considered an important and empowering element in health care reforms. It involves giving patients information that they can understand and act upon and providing support customized to their needs so that they are equipped to learn how to manage their own state of health. Activated patients develop their own understanding of and are engaged in their role within health care processes.<sup>6</sup>

A recent study in the United Kingdom<sup>7</sup> showed the potential for a lasting negative impact on patients who are not sufficiently involved in admission and discharge processes into and out of mental health care. Ensuring that these patients have a meaningful say in what is happening to them is vital. The study<sup>7</sup> also identified the loss of the patient's voice at the key transition points into and out of acute inpatient mental health care. Tveiten et al<sup>8</sup> have advised giving patients in a mental health context a voice to express their concerns and have these addressed.

Research has provided evidence of the benefits of increased patient involvement and raised the visibility of the service user, redefining integrated care and moving beyond policy aspiration.<sup>9-11</sup> A study about patients' knowledge and the power imbalance in the doctor-patient relationship supports our findings that patients need knowledge and power to participate in a shared decision-making process.<sup>12</sup> The study offered several recommendations for enhancing this by simplifying the trialled pathway and accompanying guidelines and strategies to improve communication between nurses and general practitioners (GPs). However, a discourse analysis of the concept of patient involvement pointed out the implications for the role of mental health nurses and concluded that they may need to relinquish power if true involvement of patients is to occur.<sup>13</sup>

A previous study identified that systems and procedures should be developed to ensure clear responsibilities and transparency at each stage of the pathways of care. A single person should take charge of ensuring sufficient connection and communication between inpatient and community mental health services.<sup>14</sup> Moreover, as reported earlier,<sup>15</sup> the establishment of relationships among the three parties involved (patients, inpatient staff, and community staff) was considered to be of utmost importance in the transition process between inpatient and community mental health care.

It seems obvious and simple that by informing patients and inviting them to discuss treatments options and partake in decision making, their autonomy is respected and registered in more tailored decisions likely to achieve a better outcome and fewer complaints. But there appears to be a clinical inertia to putting such shared decision making

into everyday practice. Power and trust seem to be important factors that may increase as well as decrease the patient's dependency, particularly as information overload may increase uncertainty.<sup>16</sup>

What is clear is that shared decision making is not a simple or straightforward matter. As Stiggelbout et al<sup>17</sup> put it, "Shared decision making is a complex intervention, and its implementation in healthcare will need multifaceted strategies coupled with culture change among professionals, their organizations, and patients." The concepts shared decision making and patient-centred care are increasingly prominent topics in discourse on quality in health care generally.<sup>18,19</sup> A shared decision-making process can be an especially difficult experience for those patients with profound mental health challenges. Health care professionals need to identify to what degree patients can or are able to engage with decision making,<sup>20,21</sup> not least in the context of care transitions that involve a multitude of health and social care professionals working within and across different organizational boundaries.<sup>22</sup> The movement of patients into and out of acute inpatient mental health wards is also particularly complex because of the potential for coercive practice. Importantly, the transition out of inpatient wards (discharge) back to the community is also challenging.

User involvement is widely referred to in policy, research, and practice discourses. The extent to which this impacts on individual clinical practice and care experiences is unclear. Crucially, the involvement of patients at points of transfer of care from the community to inpatient settings and back to the community is underreported. A main element in the Coordination Reforms in Norway<sup>23,24</sup> relevant for the current study is a commitment to ensure that patients receive optimal health care services through cohesive, integrated patient pathways and recommends a 24-hour follow-up in the community after discharge from hospital.

This study aimed to explore the nature of former patients' involvement and perspectives on their care pathways between psychiatric hospitalization (district psychiatric centre [DPC]) and community mental health services at key transition points.

## 2 | METHODS

A qualitative research design with a descriptive approach was used to reveal important factors in care pathways for former mental health patients.<sup>25-27</sup> Three focus group interviews were conducted with a total of 10 informants, three men and seven women with a mean age at 40 years, from (five) different communities. Prior to the focus group sessions, we discussed in great depth which questions to ask in order to obtain information on the specific topic of their own experience of the transition between hospital and community. Interviews were transcribed and analysed thematically where themes describe what patients perceived as facilitating or acting as a barrier in the transition phase.<sup>28,29</sup> In Norway, mental health community services comprise GPs and mental health nurses/social workers who collaborate with somatic health services. In addition, they are expected to cooperate with the mental health specialized services in hospitals. The hospital mental health services can advise

the communities on treatment, but the communities make their own decisions for care in terms of how often patients should be visited, what interventions or resources are provided for this from their budget, and subsequent further hospitalization or visits from ambulant teams.

## 2.1 | Process of selection of informants

The leaders in mental health volunteer organizations in the communities and a rural mental health activity centre identified experienced former mental health patients who had been hospitalized.

## 2.2 | Participants and demographics

Ten former patients from five communities who had previously experienced transition into and out of inpatient services (DPCs) were interviewed. Three were attending a rural mental health activity centre, and seven had mental health peer support roles in the communities. All informants were former patients in DPC with more than 10 years of lived experience in accessing mental health services and being subject to transition processes. They were well-placed to reflect upon what seemed to work/not work in the latter. There were seven women and three men. Because of the richness of the spoken word from the informants, their experience, and their ability to point to factors important for successful transitions, we decided that the three focus groups provided enough information power to enlighten the aim of this study.<sup>30</sup>

## 2.3 | Ethics

The study was approved by the Norwegian Centre for Research Data (NSD, project no.51960) with no additional approval required for ethical clearance. The Regional Committees for Medical and Health Research Ethics (REC) concluded that it was not necessary given that the study had full REC approval (REC 2018/1181) (presentation assessment). All phases of the study were conducted according to the Helsinki Declaration<sup>31</sup> and ethical principles in research. Data were transcribed and anonymized accordingly. Written, informed consent was obtained from all informants.

## 2.4 | Focus group interviews

We used a semi-structured interview guide developed with university and health care representatives in the focus group interviews. The informants were asked to describe their views on experiences with care pathway transitions between DPCs and community mental health services. The interviewer guided the focus group discussion according to the written set of topics: planning; cooperation between patient and staff; patient participation; ethical issues; communication including information giving and documentation in all settings; clinical care and treatment; medication; interdisciplinary collaboration; and organization of information among health personnel and patients. An

assistant moderator contributed by regularly summarizing and following up key information revealed in the group discussions.<sup>32,33</sup> At the end, we asked general, open-ended questions to gather information that had previously not been expressed. All interviews were audiotaped and transcribed verbatim. The duration of each focus group interview was 90 to 120 minutes. All interviews were recorded, transcribed, and analysed in Norwegian. Quotes that seemed to best reflect themes that emerged were selected. In order to keep interpretations close to the sociocultural context as possible and ensure interpretative validity, the translation into English was done after fulfilment of the content analysis and selection of quotes were completed.<sup>33-35</sup>

## 2.5 | Data analysis process

Thematic analysis was congruent, as well as inductive, with the statements from informants, with codes derived directly from the transcription of the interviews. The steps in analysis included familiarization with the content of the data, rereading and being aware of initial conceptualization of the data, and the generation and definition of themes according to systematic coding. Substantive codes were identified by searching for significant phrases and words line by line from the protocols. During open coding, there was a continuous comparison for similarities and differences in different parts of the data. Substantive codes with similar meanings were sorted into groups and formed categories. Also, properties and dimensions of each category as well as connections between categories were sought. All generated categories were continuously compared with each other. A core category was identified and could be related to the other categories. Four themes of care pathways emerged from final data analysis.<sup>36</sup>

## 2.6 | Data analysis

Interviews were transcribed and analysed through thematic text analysis in six phases: familiarizing ourselves with the data, coding, searching for themes, reviewing themes, defining and naming themes, and writing up.<sup>28,29</sup> A codebook was developed on the basis of variables identified by our research team at the beginning of the study as theoretically relevant to the research questions and the literature. Graneheim and Lundman's<sup>37</sup> proposed measures of trustworthiness (credibility, dependability, and transferability) were applied throughout the steps of the research procedure. Each informant was allocated a code letter in order to be recognized in the result section. Two letters are inserted when more than one informant shared the same views, either by nodding or repeating words. Through the thematic text analysis, we ended up with four main themes. The four themes emerged from the categorical content analysis. These themes are presented and participants placed themselves somewhere along a continuum for individual themes or in a dynamic oscillation between them. This is according to an analysis model earlier reported by Hasson-Ohayon et al,<sup>38</sup> which we were granted permission to use in

our study. The analysis of group-level data also involved scrutinizing the themes, interactions, and sequences within and between groups. We performed an iterative analysis in a systematic, repetitive, and recursive process. The following is an elaboration of each theme with salient excerpts typifying participant statements.

### 3 | RESULTS

Four areas of care pathways between DPCs and community mental health services emerged from the analysis as follows (Table 1):

#### 3.1 | Patient participation/activation/empowerment versus paternalism and institutionalization

The participants highlighted that they have the knowledge, skill, and confidence to manage their own health, indicating the importance of activation and participation:

*We know the importance of participating in your own life, how you experience yourself, not just which symptoms you have. (G,H)*

The following negative insight of paternalistic involvement and participation in mental health care was reported:

*...when you are related to mental health, then you don't have the codetermination any more, others which will rank over you and decide .... (G)*

The informants signalled the importance of the Norwegian Welfare Office called (name in Norwegian) NAV:

*The service declaration from NAV says that an individual plan should be written. (H, I)*

Participating in the process of setting goals together with clinical staff positively affected informant perspectives on having responsibility for their own life. However, some informants expressed that they had no sense of ownership of care documentation or power to contribute meaningfully to it:

*The staff write what they want, and it is documented forever and to have something deleted from the journal is far from routine. (G,B)*

The discharge was sometimes experienced as a struggle because there was little chance for reading the documentation of the inpatient stay before leaving:

*Often it is very hectic at discharge, and you are waiting for your medication ... and the taxi requisition etc. And then suddenly, they are standing there with a piece of paper ... and it is no time to read. (B)*

The participants also expected more thorough systems for improving care such as templates for information and a standardized plan of their care pathways:

*... If all agree that it should be done like this, just as you pay when you leave the shop, you know what to expect ... . (E)*

More discussion and participation with both staff in hospital and the community during the transition phase were wanted, and this was conveyed concisely and powerfully:

*Here is what is written about you, here is what we expect, becoming 'a part of a package.' (E, F)*

The informants emphasized that the stay as an inpatient led to a lack of self-belief and self-efficacy in remaining healthy:

*It is perhaps risky when you have been hospitalized for a while, that you forget your healthy and good side of yourself. (D,F)*

This could affect the transition phase:

*It is burdensome ... it is a vacuum, a very strange thing to leave the hospital ... . (D)*

Our informants indicated that their stay as inpatient influences cognition and sense of responsibilities about maintaining their own health, and this could affect the transition phase to the community. Having a plan and incorporation of new routines were emphasized as important at discharge.

**TABLE 1** The four themes

Themes	
Theme 1	Informed shared decision making and patient knowledge; Patient participation/activation/empowerment versus paternalism and institutionalization.
Theme 2	Ethical aspects in mental health; Patient-centred care versus care interpreted as humiliation.
Theme 3	Collaborative practice; Interprofessional collaboration or teamwork versus unsafe patient pathways in mental health services.
Theme 4	A holistic approach considering the physical as well as mental health aspects; Sustainable integrated care versus fragmented, noncollaborative care.

#### 3.2 | Patient-centred care versus care interpreted as humiliation

To master daily life, the informants pointed to the importance of having a targeted plan to cope and reduce their mental problems. For example, one individual stated

*It defines your life, what you can and cannot do, what is important and not important ... . (H)*

Patients' opinions about the kind of care they needed were not heard or taken into consideration when hospitalized:

*I have been admitted many times to a hospital, but I have never been asked how I want the service to be. (G)*

Individual wishes are neglected, invalidating their self-determination and personal knowledge:

*You felt this pressure; you are not worth anything! (C)*

The informants emphasized that they were dominated by the support system and in thrall to its decisions. As one participant commented,

*When you use force, you take the care from people, take away the choice of their therapist, then you have to grant new privileges. (C)*

However, staff who advocated for and on behalf of the patient's perspective were valued for strengthening self-esteem:

*Now I have a psychiatric nurse with ambitions on my behalf. (C)*

One informant felt that there can be too much pressure in the care pathway to improve or recover in a way that ignores real "here and now" challenges:

*I want respect for what is here and now, instead of pushing me too much. (A)*

Another informant pointed to the need for an enhanced, deeper understanding of the experience of admission by the hospital-based mental health team:

*I wish that the mental health team would ask questions of my experience of admission. (E)*

A richer understanding of people living with mental health challenges might be best achieved in the community setting. The informants emphasized the good conversation in the community as "alpha and omega" and DPC as a place they visit occasionally.

### 3.3 | Interprofessional collaboration or teamwork versus unsafe patient pathways in mental health services

NAV was identified by participants as having a mandatory task to prepare an individual care plan:

*It is basic that there is an individual plan, set up with individual goals, eventually in collaboration with those who are going to help. (E)*

The informants shared the impression that it is difficult to get an offer from NAV when they are classified as disabled. Informants also tell that the health care specialization leads to a gap in the services:

*These gaps become bigger and bigger, and patients fall between two chairs. (G,H)*

The informants experience little interprofessional teamwork between mental health care, somatic health care, and patient-led organizations. There appears to be little cooperation to advance integration across these sectors, as indicated by one respondent with salient dual health challenges:

*I'm struggling with diabetes and mental health. I have asked my diabetes nurse, if they could meet with the team from mental health. But my mental health teams say: 'Sure, they can come! But we can't go to them!' (G)*

The informants called for a clearer agenda and for more cooperative meetings between practitioners that avoid unnecessary restrictions around confidentiality of information:

*... health personnel should share information .... (C)*

Changes in personnel can bring delays in care and frustration for patients, which can significantly disrupt the transition process:

*... .then suddenly your executive nurse and all resource persons around you have changed, and you get a new, a stranger. (E)*

Our informants valued being seen and taken seriously in the meetings with professionals:

*You need good helpers to get healthy. Also given proper treatment, and be seen and taken seriously. Not all of us are able to speak for ourselves. (J)*

To be social and to participate in a user-led mental health organization helps the transition to the community:

*When out of the psychiatry, I was in a 'Mental Health' organization. I had a need of being together with others that shared my experiences. (D,F)*

The informants underlined the need to formalize a user council or a former patient group in the community. They wanted to help others with mental health problems:

*One user or two representatives who might be contact links, when in need of input. And each community should have a user consultant in mental health. (E,F)*

Regular talks with the next of kin was missing in negotiating transitions and was also underlined as important of most of the informants.

### 3.4 | Sustainable integrated care versus fragmented, noncollaborative care

An overarching Individual Plan (IP) of care as a vital tool for shifting the power imbalance that currently exists between practitioners and patients was considered important:

*If you had a plan when you were admitted the DPCs then you also had something to 'knock on the table with.' (G)*

While some informants were unsure of what an IP was (D,E), another questioned its scope:

*How can you tell me that this is a plan for my life, when there is no word about goal, and how I should achieve the goal? (H)*

Dialogue and being invited into the process at an early stage were recommended to add continuity in the transition process:

*I think it is important that at an early stage of the treatment process you are having a dialogue: 'It is perceived that you are here for ... and you want help to...then we notify the x community about the needs for follow-up.' (H)*

The informants emphasized repeatedly the importance of collaboration throughout the routine discharge meetings between staff in DPCs and community. As one respondent put it,

*It should be mandatory with several meetings between your therapists in DPC and the therapists in the community, so they could match better. (G)*

Another informant flagged up the need for community services to be more engaged and active prior to discharge:

*...The community should not resign their responsibility in the same moment you are going to be hospitalized ... and not remain passive until they get a message about your planned discharge. (H)*

Importantly, the need for continuity to be maintained by DPC after discharge and in the transition period was noted:

*It is important when you are leaving the DPC to collaborate with the DPC for a period of time ... time to build up trust and confidence to the psychiatric nurse while you still have the therapist at DPC. (C)*

Similarly, the DPC should take responsibility in preparing the patient for discharge:

*... and there is time allocated to talk about what you shall do when you are out in the community and clearly expressed what is decided, then it is probably easier for the community personnel to follow up. (F)*

The informants also identified a pressure on DPC to discharge, and patients not ready for discharge must leave. They emphasized that the community is under a huge pressure with limited staff resources in the community setting, especially for mental health nurses. They wanted smooth transitions between the DPC and community services.

## 4 | DISCUSSION

The main findings affecting smooth pathways in mental health care found in this study were as follows: (a) the desire of patients to

participate in the process of transition; (b) the need to take into account their views and values; (c) the importance of providing patients with enough information and documented plans at the right time; and (d) the importance of collaboration between mental health and other professionals to guarantee that planned activities meet patient need.

The concept of "shared decision making" is not adequate to describe what the informants participating in the study wanted to see in care pathways of transition. Our informants emphasize the need for full sharing of information in order to make the right shared decisions—"informed shared decision making" could better describe their preferred approach to achieving smooth pathways of care.

### 4.1 | Patient participation/activation/empowerment versus paternalism and institutionalization

The participants emphasized having the knowledge, skills, and confidence to manage their own health. They highlighted the importance of activation and participation and reported negative experiences that lacked involvement and meaningful engagement. Rather than notional or theoretical participation in their own care, they wanted this manifestly present in reality. Pelto-Piri<sup>39</sup> found that paternalism still clearly appears to be the dominant perspective among staff caring for patients in psychiatric inpatient care settings.

Patient participation and activation is considered an increasingly important and empowering element in health care reforms. Patient activation emphasizes patients' willingness and ability to take independent actions through understanding one's role in the care process and having the knowledge, skills, and confidence to manage one's health and health care.<sup>5,40</sup>

One of the barriers to increasing patient participation could be when they lack insight because of cognitive limitations arising from a mental health condition. But this factor alone should not prevent approaching informed shared decision making to the fullest possible extent at any time. This finding is in line with Solbjør et al<sup>41</sup> who identified how, in phases of poor mental health, patient participation demands sensitivity from staff so as to tailor this to what is perceived to be in the patient's best interest.

Documentation in these cases will be extremely important to strike the right balance to prevent routines that hold back patient participation. The right to an individual plan is grounded in Norwegian laws. Participating in the process of setting care goals together with staff advances patient autonomy and respect. The challenge is to write and form individual plans so that patients themselves are actively involved throughout the process and regard these as their own. In other words, the plan per se is not enough. It should be a dialogical and ongoing communication relevant to the patient and informed by their perspectives, hopes, and preferences. Patient involvement in their care planning should be evidence based and, in line with Grundy et al,<sup>42</sup> professionals need to engage with, explain to, and involve users across the whole process of care planning, recognizing that people living with mental health difficulties have clear and concrete

ideas as to how they want to be involved. Van Houdt et al<sup>43</sup> found that introducing care pathways across the primary hospital care continuum ensured an effective referral process by enhancing care coordination, which is in concordance with our findings.

The experience of hospitalization and the subsequent phase of moving back to the community should be accompanied by hope and a new starting point. Our informants reported limited time to read and contribute to the content of the discharge documents before leaving the hospital; being part of decisions would probably lead to better treatment compliance, and protocols should ensure that patients participate in planning discharge.

A recent study about shared decision making in mental health pointed to the importance of a deeper understanding of decisional and information needs among users of community-based mental health services that may reduce barriers to participate in decision making.<sup>44</sup> Shared decision making is more than just efforts to impart knowledge to informants. It also involves engagement and eliciting and integrating decisions.<sup>45</sup>

Although former health journals are an important source of information, mental health status and the need for treatment change. As patients perceived that too much emphasis was alleged to former health status, health staff should implement the need of patients to find out what is happening in their lives as well as the need of treatment at the present time and for the future.

As earlier suggested,<sup>14,15</sup> improved information sharing in/between all care systems is imperative in order to strengthen patients' participation in decision making and secure the follow-up of the key findings in the point of transition between services in terms of cooperation, information, and documentation.

Pathways of care can turn out to be rigid and driven by objective criteria. For patients' voices to be considered important, society needs to nurture the idea of individual treatment—a standardized plan for care pathways with room for individual needs according to the findings in this study. According to our informants, objective criteria are important, but the plans should also have room for individual needs.

As mentioned in one of the comments above, current approaches can leave patients feeling like a “package” passed between services that are failing to communicate meaningfully with each other.

## 4.2 | Patient-centred care versus offensive care interpreted as humiliation

Patient-centred care is a widely used term in the health field generally and in mental health specifically.<sup>21</sup> The patient-centred care initiative has been useful for highlighting patient preferences and values, but there is still no universally accepted definition of the term.<sup>46,47</sup> Contrary to a patient-centred approach, some of the informants in our study reported that their opinions were not heard or taken into consideration when hospitalized, with the resultant loss of self-esteem when their individual wishes were neglected. Svindseth et al<sup>48</sup> identify humiliation as occurring during the admission process to psychiatric hospitals.

In reporting a lack of control and mutual decision making in the existing care pathways between services, our respondents emphasized the role of information in such transitions. Prior meaningful discussion between patients and health personnel about transition from one service to another was considered of paramount importance. When patient perspectives on their care and transitions are overlooked, we can expect lack of treatment compliance and other counterproductive behavioural responses. Ethical challenges occur when preferred clinical interventions are challenged by the values and preferences for care held by patients. This can create a sense of doubt, discomfort, or insecurity on how one should interact or react to such situations.<sup>49,50</sup> One of the solutions could be to listen to the needs of the patient, seriously consider whether options preferred by the patient could work, and if not, present the reasons why clinical treatment/activities should be followed. Sometimes, health professionals have to decide against a patient's will or wishes. When this happens, compliance can be promoted by giving patients full and respectful information about why health personnel have to act in certain ways.<sup>41</sup>

One of the patients in our study reported that without being given any control, the psychiatrist simply had to be trusted. To achieve better treatment compliance, the transition should, as far as possible, be a shared decision with the patient. This depends on building a good relationship in the clinical encounter so that information is shared and patients are supported to deliberate and express their preferences and views during the decision-making process.<sup>51</sup> Several tools could contribute to this, not least providing the patient with enough information to be able to make informed decisions. In line with this, Miles and Asbridge pointed out that it will probably be best to move from an “evidence-based, *patient-focused*” ideology to an “evidence-informed, *person-centred health and social care*” in order to increase the person-centeredness of care provided.<sup>52,53</sup>

Shared decision making promotes the use of research knowledge, and evidence-based medicine asserts that the inclusion of patient preferences, along with scientific evidence and clinician skills, should underpin medical decision making.<sup>54-56</sup> As care pathways are grounded in evidence-based medicine and evidence-based practice, clinical guidelines and best practice should intend to realize and integrate the best research evidence with clinical expertise as well as patients value to facilitate clinical decision making.<sup>54-56</sup>

Being given the opportunity to decide on their care could also increase patients' self-esteem and thus sense of control during transitions between services, which can be stressful and experienced as paternalistic.<sup>39,42,57</sup> The informants reported that having staff advocating for them and their perspectives strengthened their self-esteem. Informants wanted to be challenged to get back into work or education but not to be pushed too hard in this regard and also to be respected for whatever level or achievement they choose to attain. This accords with Hasson-Ohayon,<sup>38</sup> who pointed to the importance of supportive relationships and work in the transition from psychiatric hospitalization to the community.

One of the informants suggested an important principle: If something is taken away from patients, something should be given back

in return. For example, the informant proposed that if their driving licence was taken, they should be empowered by access to public transport in replacement. This reciprocity could transfer to other situations as well. Some patients are reluctant to be admitted to a hospital or sometimes to go back to the community. If health personnel admit or discharge against the patient's own will, additional effort should be made to convey the benefits of being admitted or discharged.

The informants wanted the community services to be more in contact when they were admitted to hospital so that patients had the benefit of continuity on discharge and to ensure strong links between different resources and providers. Patients do not live in hospitals; they live in the community, in their own homes. The collaborative practice is therefore of the utmost importance to develop a care plan that truly and meaningfully advances community living and minimizes the likelihood of further future admissions. This will require enhanced collaboration and coordination to provide appropriate and safe care across inpatient and community care.

### 4.3 | Interprofessional collaboration or teamwork versus unsafe patient pathways in mental health services

Informants reported a lack of interprofessional collaboration between teams working in mental health, somatic health, and user-led organizations. A Norwegian study<sup>58</sup> concluded that interprofessional teamwork based on communication, shared decision making, and knowledge of professional responsibility can enhance the quality of mental health care.

Our study reveals the lack of preparing an individual plan from NAV, and such a plan is very important because of patients in need of adjusted work offers. The informants emphasized that economic constraints and health care specialization leads to gaps in coordinated services. The threshold for admission to a hospital is getting higher and higher, with those patients not experiencing severe mental health symptoms unlikely to be offered inpatient stays or, when they are, subject to premature discharge to clear beds. These limitations are impacting on the quality of transitions into and out of inpatient care.

A recent study<sup>59</sup> about service users' views regarding involvement in mental health services supports our findings that patient involvement is enhanced when they are part of the creation of care pathways and specific training for the workers. Scaria<sup>60</sup> argues that interprofessional teamwork through use of care pathways is perceived as being essential for the delivery of a high-quality service that results in patient satisfaction and that health care professionals with different sets of knowledge, skills, and talents should collaborate to achieve common goals. Scaria's informants called for good helpers among health staff who could sometimes be their "voice."

Our informants were concerned with achieving care decisions that were right for them. They did not want useful information about their needs blocked between different services. The informants wanted more mandatory meetings between DPC and community services

and a clear agenda through collaborative meetings without unnecessary caution on confidentiality. While they accepted that such meetings would be led by professionals, our informants wanted patients to be respected for their knowledge and experience and taken seriously as contributors to their own care. To counter delays and frustration for patients arising from new personnel, our informants emphasized the need for continuity in the transition process. This would best be met by at least one health professional being substantially familiar with the life of the patient. In addition, such meetings should be in advance of admission or discharge whenever feasible to allow patients enough time to be prepared for the transition.

The informants wanted more tools for activation in the community and considered participation in user-led mental health organizations as a good way to enable a smooth transition. Our informants wanted a formalized user council or a user group in the community to help share their experiences to health personnel in the community as well as help mental health patients stand up for themselves. Similar findings were identified by Bennets et al<sup>61</sup> foregrounding the role of the consumer consultant and power and change as primary themes. Our informants considered training and education of health professionals in consumer participation to be key.

Our informants noted that involvement and discussion with next of kin were often lacking. They emphasized that the family should be better informed about their condition and the actions they can take in response to changes in symptoms. A study<sup>62</sup> about patient and family views described the needs of persons with serious mental illness in discharge in three categories: engaging in the discharge planning process; making the transition smooth and guiding values; and for patients and families to have greater understanding of goals for follow-up care. Cohesive interprofessional teamwork is essential to ensure continuity in health care services, accordingly combining resources and coordinate knowledge, skills, and efforts to perform necessary tasks.

### 4.4 | Sustainable integrated care versus fragmented, noncollaborative care

Admission to a mental health institution for a long or short time should not separate one from the life in the community. Indeed, a holistic approach is necessary in order to decrease the number and length of admissions, that is, proper consideration should be given to the patient's full and diverse life and not simply be limited to their status of having mental health challenges. Practitioners should aspire towards this holistic approach.<sup>63</sup> Updating individual plans negotiated with patients should reflect such as approach. Unfortunately, our informants reported that this did not always happen. Dialogue and entering the transition process at an early stage was strongly recommended.

The DPC together with the patient and health personnel from community services should undergo a clear plan before discharge, with time allocated to decide further treatment and activities in the

community to make it easier for appropriate follow-up. A low threshold for inviting other personnel from, for example, NAV, should be initiated in order to get necessary processes started. This is in line with an earlier study.<sup>14</sup>

Improved information sharing within and/between all care systems is imperative in order to strengthen patients' participation in decision making and ownership of care plans so as to improve compliance. The importance and value for the patient of maintaining therapeutic links at DPC while in the early stages of transition back into the community were strongly recommended. Also, as reported earlier,<sup>15</sup> both digital and telephonic sharing of information and communication should be implemented before admission to a hospital-based service and before and after discharge back to the community.

The informants in our study identified problems in community services due to severe workload pressures, especially for the mental health service, and with patients not being prepared for discharge. The informants wanted more help in the underresourced community setting, particularly on evenings and weekends.

#### 4.5 | Limitations and strengths of the study

The findings of the present study are non-generalizable but offer valuable insights and understanding about the phenomena of care pathways in the transition between inpatient DPCs and community mental health services. We would like to point out that our national health system could be different from other countries. Despite the small sample size, we derived a rich and contextualized information from former patients about factors that were perceived as either facilitators or barriers in the care pathways for this transition. Such findings can assist in tailoring the organization of care pathways to enhance the patient experience of mental health care transfers. In hindsight, we see that our inclusion of patients having repeated experience of pathways of mental care could have led to having missed information of how first-time patients experience the transition between hospital and community. We acknowledge that our focus has been the health planning system in a region in Norway, and different findings may emerge from other regions in this country and other territories. Our findings indicate that further and more comparative research could test and build upon these initial findings.

## 5 | CONCLUSION AND RECOMMENDATIONS

Person-centred care seems to embrace most of the statements concerning improving pathways of care. Patients should be an active part of the treatment planning. That is, their opinions should be emphasized, and they must have time to read documents about themselves, especially during the transition period between hospitals and communities. To prevent humiliation in mental health care, person-centred care was recommended.

The need for process participation, having enough information and documented plans at the right time in the pathways, in collaboration

with the right professionals with the right abilities to make planned activities happen, was reported as important. There was a strong emphasis on having a holistic understanding of patients' health needs and meeting these with full sharing of information in shared decision making. Informed shared decision making could better describe the preferred approach to achieving smooth pathways of care. Also, 24-hour ambulant teams in the community were emphasized together with the recommendation that the community should include former patients as consultants to ensure that patients' experiences, voices, and opinions are heard.

We recommend further longitudinal research to investigate trends in patient involvement and participation in developing enhanced, well-organized transitions and specifically to determine best practices for shared interprofessional working according to pathway of care standards.

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#### CONFLICT OF INTEREST

The authors declare no conflict of interest.

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#### REFERENCES

- Botha UA, Koen L, Joska JA, et al. The revolving door phenomenon in psychiatry: comparing low-frequency and high-frequency users of psychiatric inpatient services in a developing country. *Soc Psychiatry Psychiatric Epidemiol.* 2010;45(4):461-468.
- Cole L, Houston S. Linking outcomes management and practice improvement. Structured care methodologies: evolution and use in patient care delivery. *Outcomes Manag Nurs Pract.* 1999;3(2):88-94. 53-9.
- Joint Commission Center for Transforming Healthcare, Improving Transitions of Care: Hand-Off Communications, [http://www.centerfortransforminghealthcare.org/assets/4/6/CTH\\_Hand-off\\_commun\\_set\\_final\\_2010.pdf](http://www.centerfortransforminghealthcare.org/assets/4/6/CTH_Hand-off_commun_set_final_2010.pdf) (accessed April, 2012).
- Zander K. Integrated care pathways: eleven international trends. *J Integrated Care Pathways.* 2002;6(3):101-107.
- Vanhaecht K, Panella M, van Zelm R, Sermeus W. An overview of the history and concept of care pathways as complex interventions. *Int J of Care Pathways.* 2010;13:17-123.

6. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff (Millwood)*. 2013;32(2):207-214.
7. Wright N, Rowley E, Chopra A, Gregoriou K, Waring J. From admission to discharge in mental health services: a qualitative analysis of service user involvement. *Health Expect*. 2016;19(2):367-376.
8. Tveiten S, Haukland M, Onstad RF. The patient's voice—empowerment in a psychiatric context. *Vård i Norden*. 2011;31(3):20-24.
9. Lawn S. Integrating service user participation in mental health care: what will it take? *Int J Inter Care*. 2015. Jan-Mar;URN:NBN:NL:UI:10-1-114809
10. Lègare F, Thompson-Leduc P. Twelve myths about shared decision making. *Patient Educ Couns*. 2014;96(3):281-286. <https://doi.org/10.1016/j.pec.2014.06>
11. Stromski NJ, Morrison P. Participation in mental healthcare: a qualitative meta-synthesis. *Int J Ment Health Syst*. 2017;11(1):67.
12. Annells M, Allen J, Nunn R, Petrie E, Clark E, Robins A. An evaluation of a mental health screening and referral pathway for community nursing care: nurses' and general practitioners' perspectives. *J Clin Nurs*. 2010;20(1-2):214-226.
13. Hui A, Stickley T. Mental health policy and mental health service user perspectives on involvement: a discourse analysis. *J Adv Nurs*. 2007;59(4):416-426.
14. Sather EW, Svindseth MF, Sorthe I, Hagfonn G, Iversen VC. Barriers and success factors in clinical pathways: transition process between psychiatric inpatient care and community care. *Eur J Pers Cent Healthc*. 2016;4(4):631-640.
15. Sather EW, Svindseth MF, Crawford P, Iversen VC. Care pathways in the transition of patients between district psychiatric hospital centres (DPCs) and community mental health services. *Health Sci Rep*. 2018;1(5):e37. <https://doi.org/10.1002/hsr2.37>
16. Gulbrandsen P, Clayman ML, Beach MC, et al. Shared decision-making as an existential journey: aiming for restored autonomous capacity. *Patient Educ Couns*. 2016;99(9):1505-1510. <https://doi.org/10.1016/j.pec.2016.07.014>
17. Stiggelbout AM, Weijden T van der T, De Wit MPT, et al. Shared decision making: really putting patients at the centre of healthcare. *BMJ*. 2012;344(jan27 1):e256.
18. Kelly F, Sav A, McMillan SBP, King MA, Whitty JA, Wheeler AJ. Patient-centered care: what consumers health organisations say and do. *Eur J Pers Cent Healthc*. 2013;2(4):448-457.
19. Carey A. Beyond patient-centered care: enancing the patient experience in mental health services through patient-perspective care. *Patient Experience J*. 2016;3(2):Article 8.
20. Dahlqvist-Jonsson P, Schon UK, Rosenberg D, Sandlund M, Svedberg P. Service users' experiences of participation in decision making in mental health services. *J Psychiatr Ment Health Nurs*. 2015;22(9):688-697.
21. Mahone I, Farell S, Hinton I, et al. Shared decision making in mental health treatment: qualitative findings from stakeholder focus groups. *Arch Psychiatr Nurs*. 2011;25(6):27-36.
22. Waring J, Marschall F, Bishop S. Understanding the occupational and organisational boundaries to safe hospital discharge. *J Health Serv Res Policy*. 2015;20(1\_suppl):35-44.
23. Norwegian Ministry of Health and Care Services. The primary health services of tomorrow—localised and integrated [white paper]. Oslo: Norwegian Ministry of Health and Care Services; 2014–2015. Meld. St. 26 Report to the Storting.
24. Norwegian Ministry of Health and Care Services. The coordination reform—proper treatment at the right place and right time [white paper]. Oslo: Norwegian Ministry of Health and Care Services; 2008–2009. Meld. St. 47 Report to the Storting.
25. Sandelowski M. Whatever happened to qualitative description. *Res Nurs Health*. 2000;23(4):334-340.
26. Polit DF, Beck CT. *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 10th ed. Place: Wolters Kluwer; 2012.
27. Miles MB, Huberman AM. *Qualitative Data Analysis: An Expanded Sourcebook*. 2nd ed. Place: Sage; 1994.
28. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101.
29. Clarke V, Braun V. Teaching thematic analysis: overcoming challenges and developing strategies for effective learning. *Psychol*. 2013;26(2):120-123. ISSN 0952-8229
30. Malterud K, Volkert DS, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res*. 2016;26(13):1753-1760. <https://doi.org/10.1177/1049732315617444>
31. WMA Declaration of Helsinki—Ethical Principle for Medical Research Involving Human Subjects (2017). Downloaded 16.02.18.
32. Malterud K. Fokusergrupper som forskningsmetode for medisin og helsefag. Oslo: Universitetsforlaget; 2012.
33. Krueger A, Casey MA. *Focus Groups: A Practical Guide for Applied Research*. 5th ed. Sage; 2015.
34. Squires A. Methodological challenges in cross-language qualitative research: a research review. *Int J Nurs Stud*. 2009;46(2):277-287.
35. Van Nes F, Abma T, Jonsson H, Deeg D. Language differences in qualitative research: is meaning lost in translation? *Eur J Ageing*. 2010;7(4):313-316.
36. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis. Implications for conducting a qualitative descriptive study. *Nurs Health Sci*. 2013;15(3):398-405. <https://doi.org/10.1111/nhs.120448>
37. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*. 2004;24(2):105-112.
38. Hasson-Ohayon I, Lerer G, Tuval-Mashiach R, Shamir E, Roe D. Having someone waiting for you outside: transition from psychiatric hospitalization to the community. *Psychosis*. 8(3):250-259. <https://doi.org/10.1080/17522439.2016.1145731>
39. Pelto-Piri V, Engstøm K, Paternalism EI. autonomy and reciprocity: ethical perspectives in encounters with patients in psychiatric in-patient care. *BMC Med Ethics*. 2013;14(1):49. <http://www.biomedcentral.com/1472-6339/14/49>
40. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res*. 2004;39(4 Pt 1):1005-1026.
41. Solbjør M, Rise MB, Westerlund H, Steinsbekk A. Patient participation in mental healthcare: when is it difficult? A qualitative study of users and providers in mental health hospital in Norway. *Int J Soc Psychiatry*. 2011;59(2):107-111. <https://doi.org/10.1177/0020764011423464>
42. Grundy AC, Bee P, Meade O, et al. Bringing meaning to user involvement in mental health care planning: a qualitative exploration of service user perspectives. *J Psychiatr Ment Health Nurs*. 2015, John Wiley & Son Ltd;23(1):12-21. <https://doi.org/10.1111/jpm.12275>
43. Van Houdt S, Heyrman J, Vanhaecht K, Sermeus W, De Lepeleire J. Care pathways across the primary-hospital care continuum: using the multi-level framework in explaining care coordination. *BMC Health Serv Res*. 2013;13(1):296.

44. Grim K, Rosenberg D, Svedberg P, Schön UK. Shared decision-making in mental health care—a user perspective on decisional needs in community-based services. *Int J Qual Stud Health Well Being*. 2016;11(1):30563. <https://doi.org/10.3402/qhw.v11.30563>
45. Chong WW, Aslani P, Chen TF. Shared Decision-making and interprofessional collaboration in mental healthcare: a qualitative study exploring perceptions of barriers and facilitators. *J Interprof Care*. 2013;27(5):373-379. <https://doi.org/10.3109/13561820.2013.785503>
46. Stewart M. Toward a global definition of patient centred care. *BMJ*. 2001;322(7284):444-445.
47. McCance T, McCormack B, Dewing J. An exploration of person-centeredness in practice. *Online J Issues Nurs*. 2011;16(2):1. <https://doi.org/10.3912/OJIN>
48. Svindseth MF, Dahl AA, Hatling T. Patient' experiences of humiliation in the admission process to acute psychiatric wards. *Nord J Psychiatry*. 2007;61(1):47-53. <https://doi.org/10.1080/0803948060112938>
49. Landeweer E, Abma T, Widdershoven G. Moral margins concerning the use of coercion in psychiatry. *Nurs Ethics*. 2013;18(3):304-316.
50. Lillemoen L, Pedersen R. Ethical challenges and how to develop ethics support in primary health care. *Nurs Ethics*. 2011;20(1):96-108.
51. Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med*. 2012;27(10):1361-1367. <https://doi.org/10.1007/s11606-012-2077-6>
52. Miles A, Asbridge JE. Person-centered healthcare—moving from rhetoric to methods, through implementation to outcomes. *J Eval Clin Pract*. 2017;5(1):1-9. <https://doi.org/10.5750/epjch.v5i1.1353>
53. Miles A. From evidence-based to evidence-informed, from patient-focussed to person-centered—the ongoing 'energetics' of health and social care discourse as we approach the third era of medicine. *J Eval Clin Pract*. 2017;23(1):3-4.
54. James K, Quirk A. The rationale for shared decision making in mental health care: a systematic review of academic discourse. *Ment Health Rev J*. 2017;22(3):152-165. <https://doi.org/10.1108/MHRJ-01-2017-0009>
55. Drake RE, Deegan PE, Rapp C. The promise of shared decision in mental health. *Psychiatr Rehabil J*. 2010;24(1):7-13. <https://doi.org/10.2975/34.1.2010.7.13>
56. Adams JR, Drake RE. Shared decision making and evidence-based practice. *Community Ment Health J*. 2006;42(1):87-105.
57. Hem MH, Gjerberg E, Husum TL, Pedersen R. Ethical challenges when using coercion in mental healthcare: a systematic literature review. *Nurs Ethics*. 2016;25(1):92-110. <https://doi.org/10.1177/0969733016629770>
58. Andvig E, Syse J, Severinsson E. Interprofessional collaboration in mental health services in Norway. Hindawi Publishing Corporation. *Nurs Res Pract*. 2014, Article ID 849375:8. <https://doi.org/10.1155/2014/849375>
59. Latila M, Nummelin J, Kortteisto T, Pitkanen A. Service users' views regarding user involvement in mental health services: a qualitative study. *Arch Psychiatr Nurs*. 2018;32(5):695-701. <https://doi.org/10.1016/j.apnu.2018.03.009>
60. Scaria MK. Role of care pathways in interprofessional teamwork. *Nurs Stand*. 2014; London;30(52): (Aug 24, 2016):42.
61. Bennetts W, Cross W, Bloomer M. Understanding consumer participation in mental health: issues of power and change. *Int J Ment Health Nurs*. 2011;20(3):155-164. <https://doi.org/10.1111/j.1447-0349.2010.00719.x>
62. Gerson D, Rode LE. Needs of persons with serious mental illness following discharge from inpatient treatment: patient and family views. *Arch Psychiatr Nurs*. 2012;26(4):261-271.
63. Huljev D, Padak T. Holistic and team approach in health care. *Signa Vitae*. 2016;11(Suppl 2):66-69.

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