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Doctoral thesis

NTNU
Norwegian University of Science and Technology
Thesis for the Degree of
Philosophiae Doctor
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Department of Mental Health

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Avhandlingens tittel på norsk: Utfordringer og barrierer i kliniske pasientforløp: Pasienter og helsepersonell sine erfaringer i overgangen mellom primær- og sekundærhelsetjenesten innen psykiske helsetjenester

Populærvitenskapelig sammendrag av avhandlingen på norsk

Tittel: Kliniske pasientforløp i overgangen mellom distriktspsykiatriske avdelinger og kommunens psykiske helsetjeneste

Begrepet 'pasientforløp', er nå innført også innen rus og psykisk helse og er forstått som standardiserte pakkeforløp ut fra gjeldende retningslinjer. Bak disse ligger fem målsettinger: Økt brukermedvirkning/-tilfredshet; sammenhengende og koordinerte pasientforløp; kutt i unødvendig ventetid; likeverdig tilbud over hele landet og bedre ivaretakelse av somatikk og levevaner.
Denne studien undersøker helsepersonell og tidligere pasienters perspektiver på erfarte pasientforløp mellom distriktspsykiatriske sentra og overgangen til kommunen.
Metoden har vært fokusgruppeintervjuer med bruk av intervjuguide i henhold til bestemte emner/områder. Data ble analysert med tematisk tekstanalyse.
Resultatene viser at helhetlige pasientforløp er nyttige for å etablere gode overganger mellom sykehus og kommunens psykiske helsetjeneste.
Det ble vektlagt at informert delt beslutningstaking og delt informasjon mellom alle parter i pasientforløpet er nøkkel til reell pasientmedvirkning.
Respektfull kommunikasjon må vektlegges for å unngå pasientydmykelser som kan undergrave samarbeid om behandlingen.
Tverrfaglig ambulant team (24-timers) i kommunene ble fremholdt som grunnleggende for å unngå pasienters følelse av å være glemt etter utskrivning fra sykehuset og for kontinuiteten i omsorgen.
Å gjøre seg bruk av brukerstyrte pasientorganisasjoner og /eller involvering av pårørende i overgangsprosessen kunne vært nyttig for tidligere pasienter i kommunen.
Det ble etterlyst mer fokus på tydelig dokumenterte planer for å støtte pasienter i kontakt med bolig-søking, arbeidssøking og tjenester fra NAV/velferdskontorer.
Konklusjonen er at system og prosedyrer bør utvikles videre for å sikre klar ansvarlighet, åpenhet og måloppnåelse på hvert trinn av prosessen i pasientforløpet.
Studien viser at for å oppnå en bærekraftig og integrert omsorg, så bør prosedyrene for pasientforløp også beskrive det konkrete innholdet i overgangsfasen inn og ut av sykehus og kommune.

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LIST OF PAPERS

Paper I:

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 Vol 4 Issue 4 pp 631-640.

Paper II:

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;e37. https://doi.org/10.1002/hsr2.37.

Paper III:

Sather EW, Iversen VC, Svindseth MF, Crawford P, Vasset F. Patient' perspective on care pathways and informed shared decision making in the transition between psychiatric hospitalization and the community. *J Eval Clin Pract*. 2019,1-1 DOI:10.1111/jep.13206.

ACRONYMS AND ABBREVIATIONS

CP	Care pathway
DPC	District psychiatric hospital centres
SDM	Shared decision making

DEFINITIONS

The community health care services are mentioned as a main element in the Coordination reform in Norway and is committed to ensuring that patients receive the most effective health care service possible, and 24-hour follow-up in the community after discharge from the hospital (1).

Transitional care ensures that patients care needs are met when they move across care settings (i.e., from secondary to primary care or vice versa), it includes hospital discharge, post-discharge support at the next level/location of care, and the engagement of the patient and caregiver in these processes (2).

Care pathways are defined as follows: 'A care pathway is a complex intervention for the mutual decision-making and organization of care processes for a well-defined group of patients during a well-defined period' (3,4).

Clinical practice guidelines are defined as recommendations intended to optimize patient care that are informed by a systematic review of evidence and an assessment of the benefits and harms of alternative care options (5)

Quality is defined as to what extent healthcare for individuals and groups increases the likelihood of the desired health effect and in accordance with today's professional knowledge (6).

Person-centered care/PCC acknowledge the notion of person, which calls for a holistic approach to care that incorporates the various dimensions to whole well-being (7).

Shared decision making (SDM) involves health professionals and patients working together with the goal of putting people at the center of decisions about their own treatment of care and relies on the basic of both patient autonomy and informed consent (8).

Patient activation emphasizes patients' willingness and ability to take independent actions to manage their health and care, and this equates patient activation with understanding one's role in the care process and having knowledge, skill, and confidence to manage one's health and health care (9).

SAMMENDRAG PÅ NORSK

Utfordringer og barrierer i kliniske pasientforløp: Pasienter og helsepersonell sine erfaringer i overgangen mellom primær- og sekundærhelsetjenesten innen psykiske helsetjenester

Pasienter med psykiske helseproblemer opplever vanligvis en rekke ut- og innskrivninger av sykehus. 'Overgangsomsorg' er grunnleggende for alle pasienter, siden det sikrer at deres behov blir møtt og tatt vare på når de krysser /flytter på tvers av omsorgsnivåer. Spesielt gjelder dette fra sekundær- til primærhelsetjenesten. Pasienter med psykiske lidelser kan ha en rekke komplekse behov som krever omfattende og sammenhengende leverte tjenester over tid. Omsorgen i overgangen fra sekundær- til primær helsetjeneste eller omvendt, skal sørge for at pasientenes omsorgsbehov blir ivaretatt når de krysser disse overgangene. Der er ingen standard løsning på slike hjelpebehov. Dette fordi hver person har sine individuelle behov.

Imidlertid, mange personer med psykiske helseproblemer trenger tjenester fra forskjellige helsehjelpnivåer samtidig. Dette fordi pasientene har stor variasjon i prefererte tjenester. Flere pasienter opplever barrierer assosiert med behandling innen psykisk helse. Derfor kan de trenge en enkel tilgang til ulike behandlinger og bidragsytere/personell.

Et hovedelement i 'Samhandlingsreformen' i Norge, som er relevant for den denne studien, er forpliktelse til å sørge for at pasientene mottar den mest effektive helsetjeneste som er mulig. Gjennom sammenhengende og integrerte pasientforløp, anbefales en 24-timers oppfølging i kommunen etter utskrivning fra sykehus. Målet med pasientforløpene er å oppnå optimal effektivitet og forbedre kvaliteten på omsorg slik det er prioritert /fremhevet i helsestrategiene i Norge.

Det primære målet med denne studien har vært å utforske og analysere innholdet i pasientforløp innen psykisk helse tjeneste/praksis i overgangen mellom psykiatrisk tjeneste

i sykehus (institusjon) og kommunens psykiske helsetjenester. Slik, bestreber min PhD seg på og bidrar til denne forskningsarea ved å utforske helsepersonell og tidligere pasienters erfaringer fra sykehus og psykiske helsetjeneste i kommunen. Dette kan gi en forståelse for pasientforløp i pasientovergangen mellom distrikt psykiatriske sentra (inneliggende pasienter) og kommunens psykiske helsetjenester.

I studie 1 (artikkel I og II) ble helsepersonell sine erfaringer med pasientforløp utforsket og studien undersøkte omfang og begrensninger med pasientforløp for å overvåke koordinering/ledelse i en utvalgt pasientgruppe gjennom en spesifisert tidsperiode i overgangen mellom psykiatrisk døgnomsorg og kommunen. Hensikten har vært a) Å identifisere faktorer som kan hindre implementering av den tiltenkte kliniske plan slik den er utarbeidet ved det psykiatriske sentra til kommunen og b) Identifisere strategier som støtter effektiv levering av tjenester med god kvalitet/pasientomsorg. Studien ble gjennomført med bruk av fokusgrupper med informanter fra to distrikt psykiatriske sentra (DPCs) og fokusgrupper med helsepersonell fra syv forskjellige kommuner. Fokus-gruppe intervjuene ble analyserte tematisk, og dataene ble analyserte for å identifisere konsentrerte meningsfulle enheter, kategorier og (subtemaer) temaer.

Det kom opp tre temaer i resultatene; Koordinering, Klinisk omsorg og Etikk. Hoved barrierer var svikt i kommunikasjonen, mangel på samsvar mellom behandlingen på grunn av uenighet og manglende kompetanse. Suksess faktorer var adekvat, direkte kommunikasjon og ordentlige dokumentasjonssystemer mellom helsepersonell, pasient deltagelse i fremtidige planer, og arbeidstid for ambulant team.

To hovedtemaer var identifiserte mellom personellet i kommune; Integrert Omsorg og Pasient Aktivering. Seks fremmende faktorer var identifiserte for suksessfulle pasient overganger; muligheter for å dele informasjon, implementering av systematiske planer, bruk av emeldinger, døgntjeneste, utpeke en ansvarlig helse person i hvert system for hver pasient, og involvering av pasienter og deres familier. Barrier som vanskeliggjorde pasientens overgang mellom nivåer av omsorg: Mangel på en ansvarlig person på hvert nivå av helsetjenesten, utilstrekkelig med møter, fraværet av systematiske planer, problemer med å identifisere riktig personale på de forskjellige nivåer, forsinkelser med deling av informasjon, og kompleksiteten ved NAV som påvirket pasientens verdighet negativt.

I studie 2 (artikkel III) utforskes tidligere pasienters syn på pasientforløp i overgangen mellom DPCs og kommunens psykiske helsetjeneste. Studien ble gjennomført med bruk av fokusgrupper med informanter fra fem forskjellige kommuner, og intervjuene ble analyserte tematisk hvor temaer beskriver faktorer som var oppfattet som enten tilretteleggere eller barrierer i overgangsfasen.

Det ble identifisert tre hovedtemaer: 1) Pasientdeltagelse/aktivering/empowerment kontra paternalisme og institusjonalisering, 2) Pasientsentrert omsorg kontra omsorg tolket som ydmykelse, 3) Tverrfaglig samarbeid eller teamarbeid kontra utrygt pasientforløp/omsorg in psykiske helsetjeneste, 4) Bærekraftig integrert omsorg kontra fragmentert, ikke samarbeidende omsorg/tjeneste.

Personsentrert omsorg synes å omfatte det meste av uttalelsene angående forbedring av pasientforløp. Pasientene skulle være en aktiv del av planlegging av behandlingen. Med det mente de, at deres uttalelser skulle bli vektlagt (understreket), og at de skulle få tid til å lese dokumenter om seg selv, spesielt gjennom overgangsperioden mellom institusjon (sykehus) og kommunene. For å hindre ydmykelser innen psykisk helsetjeneste, ble personsentrert omsorg anbefalt. Behovet for deltagelse i prosessen; å ha nok informasjon og dokumenterte planer til rett tid i pasientforløpet, i samarbeid med de rette profesjonelle med de rette ferdigheter til å sette aktivitetene ut i livet, var rapportert som viktig. Der var en sterk vektlegging av å ha en helhetlig (holistisk) forståelse av pasientenes helsebehov og at disse ble møtt med full deling av informasjon in en delt beslutningstaking.

SUMMARY

Background and aims

Many patients with mental health problems experience numerous transitions into and out of hospital (10). Transitional care is important for all patients, as it ensures that their needs are met when they move across care settings, specially from secondary to primary care (2). Patients suffering from mental illness can have numerous complex needs and often require comprehensive and coherently delivered services over time (11). There is no standard solution to fit everyone because every person has individual needs.

However, many persons with mental health problems need services from different levels at the same time.

Evidence shows that patients with mental health concerns often share their problems with their primary-care provider (12,13) but that primary care providers have mixed success in identifying and managing these concerns on their own (1, 14).

Because patients have a variety of preferences for care and face barriers associated with mental health treatment, this situation suggests the need for easy access to a range of treatments and providers (11,15,16).

A main element in the Coordination Reform in Norway (17), relevant for the current study, is the commitment to ensure that patients receive the most effective health care service possible, through cohesive and integrated care pathways, and recommends a 24-hour follow-up in the community after discharge from the hospital. The apparent goal of care pathways is to achieve optimal efficiency and improve quality of care as prioritized in health strategies in Norway.

Based on the mixed findings of the previous care pathway research, this thesis aimed to explore care pathways in mental health practice. An overall aim was to provide relevant

knowledge on the transition process between intermediate/acute institutions and community health services.

Thus, the current study endeavors to contribute to this area of research by exploring health personnel's and former patient's experiences in psychiatric inpatient care and community mental health services. This can provide an understanding of care pathways in the patient transition between district psychiatric centers (inpatient) and community mental health services. This thesis is based on data from two studies.

Study 1 (Papers I, II)

Rationale, aims and objectives: This study explored health personnel's experience of care pathways and examined scope and limitations of care pathways to monitor patient-care management of a selected patient group during a specified time period between psychiatric inpatient care and the community. The objectives have been to: a) Identify factors that may obstruct the intended clinical plan as devised by psychiatric hospital centres for implementation by community services and; b) Identify strategies which support effective delivery of quality care.

Method: A qualitative design with a descriptive approach was chosen to reveal important factors of care pathways for mental health patients. Seven focus- groups with a total of 18 informants were convened from two psychiatric hospital centres. Total four focus groups interviews with 12 informants from seven different communities were conducted. The focus-group interviews were analyzed thematically, and data was analyzed to identify condensed meaningful units, categories (sub-theme) and themes.

Results: Three main themes emerged from the staff at the hospital; Coordination, Clinical Care and Ethics. Main barriers were communication errors, lack of treatment compliance due to disagreement on treatment, and lack of competence. Main success factors were adequate direct communication and proper documentation systems between health personnel, patient participation in plans, and working hours of ambulant teams.

Two main themes were identified among the staff in the community; Integrated Care and Patient Activation. The participants shared their experiences on topics that can affect smooth care pathways in mental health. Six promoting factors were identified for successful patient transition: opportunities for information sharing, implementation of systematic plans, use of e-messages, around-the-clock care, designating one responsible health person in each system for each patient, and the involvement of patients and their families. The following barriers were all found to impede the patients' transition between levels of care: the lack of a single responsible person at each health care level, insufficient meetings, the absence of systematic plans, difficulties in identifying the right staff at different levels, delays in information sharing, and the complexity of welfare systems negatively affecting patient dignity.

Conclusions:

This study suggests that care pathways are useful for securing key objectives in the interface between hospital and community based psychiatric care. Improved information sharing in/between all care systems is imperative in order to strengthen patients' participation in decision-making, ownership of the care plan and improve compliance.

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 enough connection and communication between inpatient and community mental health services. Finally, both patient and staff in community services should be linked through a direct telephone number with around-the-clock availability.

Study 2 (Paper III)

Rationale, aims, and objectives: This study explored former patients' views of pathways in transition between district psychiatric hospital centers (DPCs) and community mental health services.

Method: A descriptive qualitative design with a descriptive approach was chosen to reveal important factors of care pathways for former mental health patients. Three focus-group interviews with a total of ten informants from five different communities were conducted. Interviews were transcribed and analyzed thematically where themes describe factors which were perceived as either facilitators or barriers to the transition phase.

Results: The informants shared their experiences on issues promoting and preventing successful care pathways in mental health. Four aspects of care pathways in the transition between DPC and community mental-health services emerged from the analysis: 1) Patient participation/ activation/empowerment versus paternalism and institutionalization, 2) Patient-centred care versus care interpreted as humiliation, 3) Interprofessional collaboration or teamwork versus unsafe patient pathways in mental health services, 4) Sustainable integrated care versus fragmented, non-collaborative care.

The need for patient participation in processes, the provision of enough information and documented plans at the appropriates times in care pathways, and collaboration with the appropriate professionals with the necessary abilities to make planned activities happen were reported to be important. There was a strong emphasis on having a holistic understanding of patients' health needs and meeting these needs through full sharing of information in shared decision making. 'Informed shared-decision making' could better describe the preferred approach to achieving smooth pathways of care. Additionally, the importance of 24-hour ambulant teams in the community was emphasized, and it was recommended that the

community should include former patients as consultants to ensure that patients' experiences, voices and opinions are heard.

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

1.0 INTRODUCTION

1.1 Care pathway concepts

Care pathways are a way to improve care coordination and make the patient-focused care concept operational (17). The aim of care pathways is to improve outcomes by providing a mechanism to coordinate care and reduce fragmentation and, ultimately, costs (18). In 2007, Vanhaecht et al. defined the term 'care pathway' or 'pathway' as follows: 'A care pathway is a complex intervention for the mutual decision making and organization of care processes for a well-defined group of patients during a well-defined period' (3,4). The definition from the European Pathway Association (EPA) uses the term 'care pathway' rather than 'integrated care pathways', 'clinical pathway' or 'care street'. The term 'integrated care pathway' is longer than necessary, as care pathways (CPs) are integrated by definition. Fragmented care pathways cannot exist. The term 'clinical pathway' is reserved for paths within a clinic. A care pathway is longer and includes outpatient department activities, discharge from the hospital and after-care (3,4).

The development and implementation of care pathways are based on multidisciplinary teamwork, an understanding of the practical organization of care and the integration of a set of evidence-based key interventions (3,4).

It is clear that as care pathways are not simple or straightforward but rather complex interventions, they comprise separate elements that seem to be essential to the proper functioning of the intervention; they target multiple outcomes and involve multiple interventions, and the 'active component' is difficult to specify (19,20).

Consistent with this definition, the characteristics of care pathways include 'an explicit statement of the goals and key elements based on evidence, best practice, and patients' expectations and their characteristics'. This includes a range of elements: facilitation of communication among team members, patients and families; coordination of the care process by coordinating the roles and activities of interprofessional care teams, patients and their relatives; documentation, monitoring, and evaluation of variance and outcomes; and identification of the appropriate resources (19). Thus, the aim of a care pathway is to enhance the quality of care across the continuum by improving risk-adjusted patient outcomes, promoting patient safety, increasing patient satisfaction, and optimizing the use of resources (20-22).

The term ‘clinical pathway’ has previously been used and understood in different ways (23). It was first employed in 1985 by Zander (16,24) at the New England Medical Centre (Boston, US), and the term is now internationally accepted in almost all service delivery settings and models of healthcare management (25,26). The definitions used for clinical pathways and the purposes they are intended to serve have generated some confusion. For instance, there is still no single, widely accepted definition of a clinical pathway (27). The clinical pathway has also been defined based on checklists of medical and nursing procedures, including diagnostic tests, medication and consultations, to ensure delivery of efficient, coordinated and effective programmes of care (28).

Research in somatic health care has shown that the implementation of a care pathway leads to increased or clearer documentation of care, better interprofessional teamwork (29-31) and better organized care (27,28). Care pathways may lead to better clinical outcomes (34,35). However, the ability of care pathways to lead to better clinical outcomes is organization- and pathology-dependent, which leads to inconclusive evidence to support the effectiveness of care pathways on clinical outcomes. Seys et al. (18) and Allen et al. (36) stated that a possible explanation lies in the dual complexity of care pathways, as care pathways are seen as complex interventions because they comprise separate elements that seem to be essential to the proper functioning of an intervention. Additionally, the context of care pathways implemented in complex organizations has been considered in both external and internal contexts. This twofold complexity means that assumptions about the implementation of an intervention need to be considered carefully and recognize the importance of non-standardization, multiplicity, interaction and context (18,35).

While CPs are now being developed and implemented across the international health care arena, evidence to support their use has been equivocal, and the understanding of their 'active ingredients' is poor. Reviews of evidence for CP effectiveness have focused on the use of CPs in specific patient populations. However, CPs are 'complex interventions' and are increasingly being implemented for a variety of purposes in a range of organizational contexts (34,36).

Seys et al. (28) concluded that the development and implementation of care pathways is labour-intensive and that resources should thus be optimally used. As care pathways are continuous quality improvement initiatives, actions should be taken to achieve and increase their sustainability.

1.2 The importance of investigating and strengthening patient care pathways

Transition of care is an important topic in health care. Transition of care is particularly important for patients with mental health problems who experience numerous transitions into and out of hospital.

Transitional care is important for all patients, as it ensures that their needs are met when they move across care settings, especially from secondary to primary care. It includes hospital discharge, post-discharge support at the next level/location of care and the engagement of the patient and caregiver in these processes (2). Some patients experience multiple hospitalizations for brief periods of time – a phenomenon often referred to as a 'revolving door' (37).

Importantly, these patients have diverse preferences for care and face a variety of barriers associated with mental health treatment. This context suggests the urgent need for easy access to a range of treatments and providers (15). Essential elements in this care process are open communication, well organized and delegated coordinating roles for interprofessional care team service delivery so that the service delivery is consistent with agreements reached with patients and relatives (12).

As mentioned above, both clinical pathways and care pathways are grounded in evidence-based medicine (EBM) and evidence-based practice (EBP), clinical practice guidelines and best practices, which are intended to integrate the best research evidence with clinical expertise and patients' values to facilitate clinical decision making.

There is a growing interest in extending care pathways in primary care and 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 who are in need of complex health services during a well-defined period (3,4), and although there seems to be a consensus on the importance of early intervention in the treatment of mentally ill patients (32), evidence about the relationship between care pathways and care coordination is sparse. From care pathways, high-performance teams can be built (32,36). Chew-Graham et al. (38) pointed out that, depending on its quality, communication could function as both a promoting factor and a barrier to success. Starfield (39) identified the following key elements in the integrative functions of primary care: first contact care (the use of services for each new problem), continuous care (a regular source of care over time), comprehensive care (the availability of a range of services) and coordinated care (the linking of healthcare events). These four elements are implicitly incorporated into the health care system to improve outcomes (40). Vickers et al. (41) noted that expanding integrated mental health care in the primary care setting/services resulted in increased staff and provider satisfaction.

A study (43) evaluating the effectiveness and satisfaction outcomes of a mental health screening and referral clinical pathway for community nursing care showed that the use of a structured pathway by generalist community nurses may result in better recognition and management of problems than nurses' reliance on judgement alone. When studying the effectiveness of a care pathway model in community mental health in the UK, Khandaker et al. (43) found that it led to more focused interventions being offered. However, Steinacher et al. (44) investigated the changes due to the implementation of care pathways in the treatment of patients with schizophrenia and found that the patients reported less treatment satisfaction after the implementation of care pathways. Steinacher et al. (44) offered no explanation, and evidence for such pathways continues to be contested or in development. Katschnig (45), for example, emphasized the importance of monitoring different levels of health care to find the best models or pathways of care. Waters et al. (46) suggested that documentation does not reflect patients' views on treatment. However, several studies have revealed that care pathways improve the components of care coordination (47, 48).

Thus, the current study endeavours to contribute to this area by exploring the experiences of health personnel and former patients of care pathways in psychiatric hospitals and community mental health services at key transition points.

1.3 Influence of patient impairment on care pathways' effects

A recent study in the UK (10) showed the potential for a lasting negative impact on patients who are not sufficiently involved in the numerous admission and discharge processes of mental health care. Ensuring that these patients have a meaningful say in what is happening to them is vital. The study (10) also highlighted the loss of the patient's voice at the key transition points into and out of acute inpatient mental health care. Tveiten et al. (49) advised giving patients in mental health contexts a voice to express their concerns and have them addressed. Pelto-Piro (50) found that paternalism still clearly appears to be the dominant perspective among staff caring for patients in psychiatric inpatient care settings.

In a recent study (51) of psychiatric inpatient care, it was indicated that creating reliable treatment and care processes, a stimulating social climate in wards, and better staff-patient communication could enhance patient perceptions of feeling safe in inpatient care.

The concepts of shared decision-making and patient-centred care are increasingly prominent topics in the discourse on quality in healthcare generally (52,53). As Stiggelbout et al. (54) stated, ‘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’. Knowledge from implementation science suggests that staff personnel need to see the benefits of patients embracing a new way of working (55).

Patient-centred care is a widely used term in the health field generally and in mental health specifically (56). 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 (57,58).

Research has provided evidence of the benefits of increased patient involvement and has increased the visibility of the service user, redefining integrated care and moving beyond policy aspiration (59-60). A study about patients’ knowledge and the power imbalance in the doctor–patient relationship supports our assertions that patients need knowledge and power to participate in shared decision-making processes (61). The study offered several recommendations for enhancing patients’ participation by simplifying the trialled pathway and the accompanying guidelines and strategies to improve communication between nurses and general practitioners. 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 to patients if true involvement is to occur (62).

It seems obvious and simple that when patients are informed and invited to discuss treatment options and partake in decision making, their autonomy is respected and their perspectives are considered in more tailored decisions, that are likely to achieve better outcomes and generate fewer complaints. However, there appears to be clinical inertia in implementing such shared decision making in everyday practice. Power and trust seem to be important factors that may increase as well as decrease patients' dependency, particularly as information overload may increase uncertainty (63).

A previous study identified that systems and procedures should be developed to ensure clear responsibilities and transparency at each stage of pathways of care. A single person should be responsible for ensuring sufficient connection and communication between inpatient and community mental health services (11). Moreover, as reported previously (31), the establishment of relationships among the three parties involved (patients, inpatient staff, and community staff) is of utmost importance in the transition process between inpatient and community mental health care.

User involvement is widely referred to in policy, research and practice discourses. The extent to which these discourses have 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 has been underreported.

1.4 Studies assessing clinical care pathways

The included studies focused on care pathways in the transition between psychiatric hospital and community mental health services. We limited the search to publications between 2009 – 2019 to allow a broad scoping review of the published research.

1.4.1 Systematic reviews

Allen et al. (2009) reviewed high-quality randomized controlled trials (RCTs) between 1980 and 2008, focusing on adults and children who accessed health-care settings in which integrated care pathways (ICPs) were used. They found that care pathways are effective with patients with predictable mental health symptoms. Care pathways improve documentation, communication and change professionals' behaviour positively (64). Rotter et al. (2010) conducted a meta-analysis to assess the effect of CPs on professional practice, patient outcomes, length of stay and hospital costs. In this review, studies were grouped into those comparing clinical pathways with usual care and those comparing clinical pathways as part of a multifaceted intervention with usual care. The finding suggested that CPs reduced in-hospital complications and improved documentation without negatively impacting the length of stay and hospital costs (65). Anderson et al. (2010) conducted a systematic review on the nature and determinants of the pathway to care of patients experiencing a first psychotic episode. Articles published between 1985 and 2009 were identified through database and manual searches. Studies were included if they used an observational design and presented quantitative data on the pathways to care of patients with first-episode psychosis and explored the first contact in the pathway and/or referral source that led to treatment. The authors did not find consistent results across the studies that explored the sex, socio-economic, and/or ethnic determinants of the pathway, and they concluded that additional research is needed to understand the help-seeking behaviour of these patients, the service response to them, and the determinants of pathways to mental health care. (66). Viggiano et al. (2012) reviewed current models and initiatives in general and specifically in mental healthcare and proposed an intervention framework. The included studies were published, peer-reviewed models and published or peer-reviewed articles that reported a (clinical) trial or demonstration study that evaluated a model. Several of the models and initiatives focused specifically on mental health populations, but it was found that a core set of transition intervention components could stimulate the development of interventions at the patient, provider and system levels. One of the nine core elements that was identified to be important for interventions to address transitions in the mental health population more effectively was care pathways with special clinical/procedural guidelines and instructions (i.e., what to do when) and links to national guidelines provided in the transition phase or at the site of care (pre-hospital, hospital, outpatient, home) (67).

Durbin et al. (2012) conducted a scoping review of the evidence on the quality of information transfer between primary care physicians and specialist mental health providers for referral requests and after inpatient discharge. The study included mostly audit studies of the content and/or timing of written communications between primary care and specialist mental health providers. In addition, information change was also evaluated. Both surveys and qualitative studies of physician and patient experiences related to information transfer, especially the quality of referral letters from both primary care and specialist mental health providers, had been conducted; the review showed the variation in the quality of communication between CPs and mental health specialists and found that patient-centred care was among the least investigated topics (68). Deneckre et al. (2012) performed a systematic review of the effectiveness of care pathways in promoting teamwork using a 'mix methods' approach, i.e., both effect evaluation and exploratory evaluation studies were considered for inclusion. The study revealed that CPs have the potential to support interprofessional teams in enhancing teamwork. The most frequently positive effects were on staff knowledge, interprofessional documentation, team communication and team relations (69). Vigod et al. (2013) performed a systematic review of interventions aimed to assist in the successful transition from inpatient to outpatient care for adult inpatients in psychiatric units. Of the included studies, there were eight RCTs, five controlled clinical trials and two cohort studies. It was concluded that transitional intervention components are feasible and likely to be cost-effective. Seven successful components were identified that reduced hospital readmission; facilitated pre-discharge, post-discharge and transition processes; and promoted timely communication of inpatient staff with outpatient care or community service providers after discharge (70).

Volpe et al. (2015) evaluated studies that used a standardized quantitative methodology to describe the pathways to mental healthcare of adult patients who were presenting for the first time to psychiatric services to identify referral delay differences between countries. It was found that the role of GPs could either decrease or increase the referral time. The authors highlighted that considerable variations in pathways to mental healthcare across different countries still exist. Stigma and discrimination towards patients with mental illness are limiting factors for the equal delivery of mental healthcare (71). Chen et al. (2015) (72) used a scoping review method conducted in accordance with the preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines (73) (Moher et al., 2009). Only papers that provided full reports addressing outcome indicators were included. It was found that care pathways showed promising results in increasing the quality and efficiency of care for patients diagnosed with schizophrenia but that more evidence was needed (72). Gronholm et al. (2017) performed a systematic review that assessed the findings of qualitative, quantitative and mixed-methods research studies focusing on the relationship between stigma and care pathways among patients with first-episode psychosis and at-risk groups. The data synthesis involved a thematic analysis of the qualitative findings, a narrative synthesis of the quantitative findings, and a meta-synthesis combining the results. Six themes were identified related to the relationship between stigma and care pathways among people experiencing first-episode psychosis or at a clinically defined risk of developing psychotic disorder. The findings indicated that a lack of information could result in increased perceived stigma (74). Doody et al. (2017) performed an integrative review in which electronic databases and grey literature were searched for papers published between 2005 and 2016 to explore families' experiences of engaging in care planning within adult mental health services. The articles were assessed for eligibility, and their qualitative and quantitative findings were synthesized. Families perceived that care planning was uncoordinated and that their lived experiences were not always appreciated; they did not regularly experience collaborative decision making but did experience communication constraints, protection of confidentiality and providers' claims of 'insider knowledge' of service users (75).

Amaral et al. (2018) performed a systematic review of pathways to mental health care in Brazil using a narrative synthesis of quantitative and qualitative studies. The findings indicated the importance of the first contact in pathways to mental health care, that a high proportion of patients are treated in specialized services, and that there is a lack of integration between emergency departments, hospitals and community services (76). Storm et al. (2019) (77) performed a scoping review (78) by analysing qualitative and quantitative studies. The study included studies focused on transitions from psychiatric hospitals to communities, including a description of programmes and interventions that aimed to improve transitions for people with serious mental illness. It was emphasized that people with serious mental illness faced challenges with adjustment and continuity of care during transitions. Effective coordination of pathways of care resulted in better improvements in service utilization, social functioning and quality of life. Shared decision-making support for caregivers was found to be important, especially when patients needed complicated medication regimes (77). A recent review study (79) included studies that examined the experiences of mental health patients as they transitioned from an inpatient treatment setting back into their communities. The included studies were empirical papers, both qualitative and quantitative, and the results of each article were qualitatively analysed using the method outlined by Thomas and Harden (80). Mutcheler (2019) (79) identified themes related to transition, patient safety, supported autonomy, and activities in the community. Barriers were poverty, interpersonal difficulties and stigma. The results highlighted the disconnect that occurs for patients as they transition from hospitals back to their communities, indicating the need for effective transitional interventions that target these challenges (79). Neame et al. (2019) performed a systematic review of the effects of implementing clinical pathways supported by health information technologies, and all types of studies were included. It was found that health information technology supported care pathways and improved objectively measured patient outcomes (81). The characteristics on the 15 review studies is shown in Table I.

Table I Characteristics of review studies

Author and country of origin	**Aims**	**Study design**	**Data collection and instruments**	**Study sample**	**Results**
Allen et al., (2009).UK.	Identify the effectiveness of care pathways in mental health settings presented in a narrative way.	Systematic review of seven randomized controlled trials published 1980-2008. Using flow chart and RCT method.	Using Medline, CINAHL, Cochrane. Use three stages strategy and three stages filtering process.	Seven studies from different countries with adult and child in mental health. English, Germany and French translation was available.	Care pathways are most effective in patients with predictable managing of mental symptoms to support proactive management and is more uncertain when including patients with more uncertainty in behavior. Pathways of care could also improve documentation, communication and change professionals´ behavior in desired direction.
Amaral et al., (2018). Brazil.	Explorative systematic review to highlight evidence for each pathway stage.	The review synthesized narrative for the 25 studies ranging from 1999 to 2017.	LILACS; MEDLINE; SCIELO databases used to searched for paper. 25 studies included. 9 quantitative and 14 qualitative and two mixed methods.	In all 25 studies were from Brazil. Both patients and health personnel views were included.	Complex social networks were involved in the studies and the points of first contact varied. A high proportion of patients is treated in specialized services and there is a stressing lack of integration between emergency, hospital and community.
Anderson et al., (2010). Canada.	Examine the associations between pathways of care and sex, socio economic and ethnical determinants of pathway, and duration of untreated psychosis as well as help-seeking behavior.	Systematic review with inclusion of 30 papers from 1985 and 2009 in 16 countries, with both quantitative and qualitative design.	Using Medline, HealthStar, EMBASE, PsycINFO databases. Then manual search in 15 journals.	In all 30 studies from Australia, Asia, USA, Africa, Europa. Both patients, relatives and health personnel views were included.	They did not find consistent results across the studies that explored the sex, socio-economic, and ethnic determinants of the pathway. More research needed to understand disparities between pathways of care and which factors that could increase patients help-seeking behavior.

Table I (continued)

Author and country of origin	Aims	Study Design	Data collection and instruments	Study sample	Results
Chen et al., (2015). Canada.	Evidence to improve quality and efficiency of care for patients with schizophrenia	Scoping review methods following PRISMA guidelines. Metanalysis not being done due to differences in methods in the papers.	Paper from MEDLINE, PsycINFO, Health Star, EBM Review Cochrane Database. 7 focused on describing process-related data and 6 examined clinical outcomes	In all 13 papers (Hong Kong, Germany, UK) were included from 1998 to 2014. Inclusion criteria narrowed to people suffering from. schizophrenia. Both patients and health personnel views were included.	Finings in three areas: Content, development, effectiveness. Pathways of care show promising results in increasing quality and efficiency for patients with a diagnosis of schizophrenia, but more evidence is needed.
Deneckere et al., (2012). Belgium.	Explore the relationship between effectiveness and how care pathways promote teamwork.	Systematic review with inclusion of 26 relevant studies.	Systematic literature search strategy in three electronic databases – MEDLINE, Embase, and CINAHL, combined with Mesh and non-Mesh terms for care pathways and teamwork	In all 26 studies used the result of an international expert panel on team indicators in care processes to identify search terms.	That was frequently mentioned the need for a multidisciplinary approach and educational training sessions. Necessary conditions are a context that support teamwork and to achieve these, each care pathways requires a clearly defined team approach customized to the individual teams 'needs.
Doody et al., (2017). Ireland.	Identify families' experiences of care planning involvement in adult mental health services.	Review was guided by a framework which is a methodological approach allowing for concurrent synthesis of qualitative and quantitative research methods	review where electronic databases and grey literature were searched for papers published between 2005 and 2016 from CINAHL, Scopus, Web Science, PsyInfo, MEDLINE, PsyArticles.	In all 15 papers from UK, USA, Sweden, Norway, Italy, Israel met the inclusion criteria. Thematic analysis generated three themes.	1: Families' experiences and collaboration, 2: families' perceptions of professionals and 3: families' impressions of the care planning process. Collaborative decision-making was not regularly experienced by families, lack of communication, confidentiality constraints and a claim of 'insider knowledge' of service users. Care planning were perceived to be uncoordinated and their lived experiences not always appreciated.

Table I (continued)

Author and country of origin	**Aims**	**Study design**	**Data Collection and measurement**	**Study sample**	**Results**
Durbin et al,. (2012). Canada.	To get evidence on the quality of information transfer between primary care physician (PCP/GP) and specialist mental health providers for referral requests and after inpatient discharg	A scoping interview of the literature was conducted to generally explore evidence of information exchange between GPs and specialists	Bibliographic academic databases were searched for the period 1995 – 2011 (MEDLINE, Embase, CINAHL, and PSYC INFO Scius and Google Scholar. Org. websides)	In all 32 paper and the librarian also explored the gray literature using sources suggested by the Cochrane Collaboration, were searched.	The study showed variation in the quality of communication between GPs and mental health specialist, although care management inevitably requires collaboration among many providers to meet patients need over time. Patient- centered care, such as explaining the purpose of a consultation request to the patient, need attention, being among the least investigated in the review literature
Gronholm et al., (2017). UK/Australia	Examine stigma related influences on pathways of care in each stage of the pathway in first episode psychosis.	Review which included quantitative, qualitative and mixed methods studies from 1996 and 2016.	CINAHL, EMBASE; Medline, PsycINFO were used. Data synthesis was conducted in three stages. First thematic analyze, was undertaken to synthesize the finding of articles reporting qualitative data. Second narrative synthesis, third stages involved a meta-synthesis.	In all 40 studies. Both patients and health personnel views were included. People aged up to and including 40 years.	Lack of information could result in increased perceived stigma. Patients also perceived devaluations by service providers. Perceived stigma reduction could decrease if treatment were normalized as sell as working with info to environment.
Mutschler et al., (2019). Canada/USA/UK	To capture and consolidate the current understanding of the experiences of individuals post-discharge who are transitioning back into their communities	Systematic review. Both quantitative and qualitative design is included. PRISMA flow chart	Systematic literature search, following PRISMA guidelines. Using Medline, PsycINFO, Google Scholar, HealthStar. Included 27 papers from a variety of countries	In all 27 paper were included. 18 quantitative and 9 qualitative papers. Only patient perspectives. All papers lacking patients´ experiences were excluded	Themes identified as necessary for transition were patient safety, supported autonomy, and activities in the community. Barriers were poverty, interpersonal difficulties and stigma. All pointing to the need of targeting the identified challenges.

Table I (continued)

Author and country of origin	Aims	Study design	Data Collection and measurement	Study sample	Results
Neame et al., (2019). UK.	Explore the effects of implementation of health information technologies in care pathways.	Systematic review with inclusion of 44 papers Systematic literature search, following PRISMA flow chart.	Using Medline, EMBASE, CENTRAL. 94% reported from hospital care and treatment and 6% from community service.	44 paper focused on health technology Electronic documentation. 16 were before-and-after studies,14 were noncomparative, 5 were interrupted time series studies, 4 were retrospective cohort studies, 2 were cluster randomized controlled trials, and there were 1 each of controlled before-after, prospective case-control, and prospective cohort studies	Some evidence that health information technology improving objectively measured patient outcome (mortality, patient-reported outcome measures, biochemical markers, and disease activity). More research is needed.
Rotter et al., (2010)Cochrane/ Germany	To assess the effect of clinical pathways on professional practice, patient outcomes, length of stay and hospital costs	Randomized controlled trials, controlled clinical trials, controlled before and after studies and interrupted time series studies comparing alone in clinical pathways with usual care as well as clinical pathways as part of a multifaceted intervention with usual care.	Searched the Database of Abstracts and Reviews of effectiveness (DARE), The Effective Practice and Organization of Care (EPOC) Register, the Cochrane Central Register of Controlled Trials (CENTRAL) and bibliographic databases including MEDLINE, EMBASE, CINAHL, NHS EED and Global Health	In all 28 studies included. Two review authors independently screened all titles to assess eligibility and methodological quality. Studies were grouped into those comparing clinical pathways with usual care and those comparing clinical pathways as a part of a multifaceted intervention with usual care.	Clinical pathways are associated with reduced in-hospital complications and improved documentation without negatively impacting on length of stay and hospital costs. (Author's conclusions).

Table I (continued)

Author and country of origin	**Aims**	**Study design**	**Data Collection and measurements**	**Study sample**	**Results**
Storm et al., (2019). Norway /USA	Examine effective coordination between levels of care, challenges in providing continuity of care and quality of life in the transition process.	Scoping review design followed Arkey & O`Malley´s (2005) five- stage framework.	CINAHL; Cochrane, Medline, PsycInfo, Google scholar was used. Systematic review with inclusion of 16 papers with qualitative and quantitative design.	In all 16 paper. Both patients and health personnel views were included. Paper from USA, Japan, UK, Canada. Individual with mental illness >18 years.	Effective approaches addressed coordination challenges and resulted in better improvements in service utilization, social functioning and quality of life. Shared decision-making support for caregivers and addressing the challenges when patients are need of complicated medication regimes.
Viggiano et al., (2012). USA	To provide an overview of current care transition intervention frameworks and models, and to identify components suited for more effectively managing transitions among persons with mental illness.	A review of intervention models identified multiple models.	PubMed, Google scholar, and grouped into two categories. 1.Models that have been put forward and tested in the area of medical care.2.Information about framework, conceptual models or descriptions of care transitions intervention.	In all nine papers about transitions from hospital to outpatient care. Managing transitions among persons with serious mental illness	A core set of nine care transitions intervention components can stimulate the development of interventions that address transitions in the mental health population more effectively, both in patients, provider and system levels.
Vigod et al., (2013). UK.	To describe and evaluate interventions applied during the transition from in-patient to out-patient care in preventing early psychiatric readmission.	Systematic review of 15 paper about transitional interventions among adults admitted to hospital with mental illness where the study. outcome was psychiatric readmission.	Medline, CINAHL, EMBASE, PsycINFO and the Cochrane Library.	I all 15 papers about transition from in-patient to out-patient care in reducing early psychiatric readmission among adults with mental illness.	Effective transitional intervention components are feasible and likely to be cost-effective All results are consistent with the findings of a previous review of pre-discharge interventions in psychiatry.

Table I (continued)

Author and country of origin	**Aims**	**Study design**	**Dasta Collection and measurement**	**Study sample**	**Results**
Volpe et al., (2015). Romania	Comparison of mental health pathways in 23 different countries around the world.	Due to different instruments and gathering of data, the planned comparison could only be performed at a few variables. PRISMA flow chart.	From MELINE, OVID, EMBASE, PSYCINFO. Reference list from 1986 to 2013 with majority of studies from 2005 and newer.	A global perspective of 34 papers on psychiatric pathway. Both patients and health personnel views were included. Studies from different country and continent.	Identified referral delay differences between countries with a range from Romania, Cuba, Bangladesh and Albania to 25 weeks before seeing a psychiatrist. Also, the role of a general practitioners could either decrease or increase the referral time. No direct comparison of data concerning the pathway to mental healthcare at the world level, is available yet.

1.4.2 Primary studies

Khandaker (43) evaluated a care pathway model for community mental health services (‘payment by result’) in the UK by interviewing doctors, multidisciplinary staff and trust managers. It was found that the model led to more focused interventions being offered and implemented in pathways, resulting in positive changes; staff were held accountable for clear standards of care. Care pathways were effective and allowed for active case management and clear clinical leadership. Arbitrary time frames, strict criteria and thresholds for different teams could create issues. Improved communication, a flexible and patient-centred approach, staff supervision, and increased support in primary care were felt to be central to this model working efficiently and effectively. The study was qualitative, involving interviews with doctors, multidisciplinary staff and trust managers.

Steinacher (44) tested (using a questionnaire) the effects of clinical care pathways for schizophrenia in open general psychiatric wards in Germany with two different implementation strategies. Surprisingly, however, the patients’ subjective judgements of their conditions on all four scales that were used to assess these variables were worse after the pathway implementation than before. The authors offered no explanation for their findings.

Van Houdt et al. (2013) conducted an in-depth analysis of the relationship between care pathways and care coordination in five existing local community projects located in four different regions of Belgium. Data were gathered using mixed methods, including structured face-to-face interviews, participant observations, documentation and a focus group, and a multi-level framework was used to explain care coordination. The construction of a new structure and use of an existing structure had positive effects on exchanging information; formulating and sharing goals; defining and knowing each other’s roles, expectations and competences; and building qualitative relationships (48).

The data presented in Wright et al. (2015) (10) were collected in a study focused on knowledge sharing at points of transition of care into and out of inpatient mental health services.

The author used focus groups with mental health nurses, teams (for example, community team staff) and service users. The findings showed a loss of the voice of service users at key transition points into and out of acute inpatient care. Due to the lack of resources (inpatient beds and community care follow-up), the role that service users could play was diminished. In their own quotes, clinical staff associated the person with the process and used language that dehumanized the person. It was concluded that these encounters can have lasting negative effects, indicating the importance of ensuring that service users have a voice in determining what happens to them.

Seys et al. (2017) conducted a multicentre study analysing whether care pathways lead to better organization of care processes using the Care Process Self-Evaluation Tool (CPSET). The study included 2692 questionnaires from organizations in Belgium and the Netherlands. A significant difference was found between care processes with and without care pathways, with care process with care pathways showing better CPSET overall scores and subscale scores for ‘coordination of care’ and ‘follow-up care’ in primary care (35). The Care Process Self-Evaluation Tool (CPSET) has five dimensions related to the organization of care processes: Patient-focused organization, Coordination of the care process, Communication with patients and family, Collaboration with primary care, and Monitoring and follow-up of the care process (82,83).

In a Norwegian study, Biringer et al. (2017) also used the CPSET and conducted a multilevel analysis to compare and evaluate care processes with and without standardized care pathways. In Norway, the sample was larger than the samples used in comparable international studies.

However, Norwegian employees considered follow-up care processes and collaboration with primary care to be poorer than the other dimensions of care organizations. Care processes with written clinical procedures were reported to be better organized than processes without such standardization. The study concluded that specialist health services should improve the systematic follow-up of care pathways as well as collaboration with primary care (83).

The study by Akehurst et al. (2018) was the first UK study focused on implementing and using localized, online evidence-based care pathways (Health Pathways) in health and social care. The study used a mixed-methods approach across primary and secondary care with semi-structured interviews and focus groups. The study was time-limited, with limited quantitative data available for analysis. It was found that the use of pathways increased over time. The themes developed in relation to online care pathways showed that care pathways were used in leadership, relationships and networks to support decision making and referrals and provided information on the availability of resources. Inter-related themes were arranged into configurations consisting of contextual influences, mechanism and outcomes. Recommendations were made for future implementation of such care pathways, such as the use of improved data collection processes to understand how and why there was variance in the use of pathways (84). The characteristics on the seven primary studies is shown in Table II.

Table II Characteristics of primary studies

Author and country of origin	**Aims**	**Study design**	**Data Collection and measurements**	**Study sample**	**Results**
Akehurst et al. (2018). UK.	To understand what contextual influences, mechanism and outcomes affect the implementation and use of localized, online care pathways (Health Pathways) in primary and secondary care.	Mixed-measures design. The study methodology draws on the realist approach to evaluation, providing an explanatory analysis aimed at showing what works for whom, under what circumstances, in what respects and how in order to provide an in-depth understanding of an intervention and how it can be made to work most effectively.	Quantitative data included number of page views and conditions viewed. Qualitative data from semi-structured interviews and focus groups were gathered over a 6-month period and analyzed using NVivo software.	General practitioners, nurses, practice managers, hospital consultants and system leaders	Use of pathways increases over time. *Themes developed*: showing online care pathways used – leadership, pre-existing networks and relationships; development of systems and processes care pathways, use of online care pathways to support decision-making and referral, and availability of resources. *Inter-related themes*: contextual influences, mechanism and outcomes. *Recommendation*: improved data collection processes to understand how and why variance in the use of pathways.
Biringer et al. (2017) Norway.	To assess health care personnel's perceptions of the organization of care processes in the specialist service in Norway. A further goal was to examine whether the staff considered the organization to be better in the care processes that were standardized using clinical procedure compared to pathways without procedure.	Assessing health care personnel's perceptions of how well the patient focused care was organized, the treatment for the patient groups were coordinated, communication with patient and family, the collaboration with primary care, and whether the standardization of care processes was followed up.	Care Process Self-Evaluation tool (CPSET) was used to evaluate how interprofessional teams in the specialist health service about their experiences with the organization of the treatment for specific patient groups.	Staff took part from a total of six somatic hospitals and six psychiatric units in western Norway Regional Health Authority, were asked to complete the CPSET. Analyzes were based on responses from 239 employees in 22 valid care processes (48 per cent response rate).	The CPSET in the sample was higher than comparable international figures. However, Norwegian employees considered the follow-up of the care processes and the collaboration with primary care to be proper than other dimensions of care organization. Care processes with a written clinical procedure were better organized than process without such standardization.

Table II (continued)

Author and country of origin	**Aims**	**Study design**	**Data Collection and measurements**	**Study sample**	**Results**
Khandaker et al. (2013) UK.	To evaluate how a model 'payment by results' for mental health works out in community mental health practice, including its impact on quality of patient care, mental health professionals and primary care.	A theoretical sampling method was used to identify members of community care pathways involved in directly patient care (e.g. inpatient ward, crisis and home treatment teams).	In total 19 interviews. Each participant took part in a private one-to-one in-depth face to-face interview at his/her own work place lasting up to an hour. Recorded interviews were coded and analyzed thematically using grounded theory approach.	Doctors, multidisciplinary staff and Trust managers in community and in acute care (e.g. inpatient ward, crisis and home treatment teams).	The model led to more focused interventions being offered and working in pathways was generally seen as a positive change; practitioners being held account over clear standards of care, more cost-effective and allows for active case management and clear clinical leadership. The arbitrary time frame, strict criteria and thresholds for different teams could create issues. Improved communication, flexible and patient-centered approach, staff supervision, and increasing support to primary care were felt to be central to this model working efficiently and effectively.
Seys et al. (2017) Belgium.	Care pathways are better perceived than care processes organized without care pathways. To evaluate the extent to which team scores correlate for care processes with or without care pathways.	Multilevel analysis was used to compare care processes without and with care pathways. Almost all care processes were evaluated either before implementation of a care pathway, during the development phase or after implementation	The statistical analysis included 2692 questionnaires from 87 Belgian organization and 21 organization from Netherlands Care Process Self-Evaluation tool (CPSET) was used to evaluate how healthcare professionals perceived the organization of care processes	In all 108 organizations from Netherlands/Belgian; acute hospitals, psychiatric hospitals, specialized hospitals and primary care.	A significant difference between care processes with and without care pathways was found. A care pathway in use led to significant better scores on the overall CPSET scale and subscales, 'coordination of care' and 'follow-up of care'. Physicians had the highest score on the overall CPSET scale.

Table II (continued)

Author and country of origin	**Aims**	**Study design**	**Data Collection and measurements**	**Study sample**	**Results**
Steinacher et al. (2012) Germany.	To determine whether the implementation of a pathway would improve diagnosis and treatment in conformity with published guidelines.	Quantitative study with a prospective, controlled design (a two-year process).	Questionnaires (before and after pathways). Differences between patients in ward A and B and longitudinal (pre and post) between patient groups.	In all 114 patients with schizophrenia in open, general psychiatric wards, where treatment pathways were implemented in two different ways.	The patients reported less treatment satisfaction after the implementation of the pathways. They offered no explanation for their findings. No significant intergroup differences between groups in ward A and B were found.
Van Houdt et al. (2013) Belgium.	To assess the extent to which care pathways support or create elements of the multi-level framework necessary to improve care coordination across the primary-hospital care continuum.	An in-dept analysis of five local community projects located in four different regions to determine whether the available empirical evidence supported or refuted the theoretical expectations from the multi-level framework.	Data were gathered using mixed methods, included structured face-to-face interviews, participant observations, documentation and a focus group. Multiple cases were analyzed performing a cross case synthesis to strengthen the results.	Staff from five local community projects located in four different regions in Belgium (hospitals and home care).	The construction of a new and use of an existing structure had a positive effect on exchanging information, formulating and sharing goals, defining and knowing each other's roles, expectations and competences and building qualitative relationships.
Wright et al. (2015) UK.	To explore the nature of service user involvement in the admission and discharge process into and out of acute inpatient mental health care.	A qualitative study using focus group interviews were conducted winter 2013-2014.	Focused on knowledge sharing at the points of transition of care in and out of inpatient mental health services in seven focus group interviews. A semi-structured interview-guide were used and lasted for approximately 60 min.	Staff from acute, inpatient mental health ward, community staff and service user (total number of participants = 52).	Due to the lack of resources (inpatient beds and community care follow-up), the role service users could play was diminished. In their narratives, clinical staff associated the person with the process and used language which dehumanized the individuals

1.4.3 Quality assessment

The aims of the six of the 15 review articles with *quantitative data* were as follows: identify the effectiveness of care pathways in mental health (Alan); provide evidence to improve the quality and efficiency of special diagnostic groups (Chen); assess the effects of pathways on practice, patient outcomes, length of stay and hospital costs (Rotter); provide an overview of care and identify components for more effective transitions (Viggiano); describe and evaluate interventions in the transition from inpatient to outpatient care (Vigod); and compare mental health pathways in 23 different countries (Volpe).

Of the 9 of 15 articles with *both quantitative data and qualitative data*, the aims included examining the duration of untreated psychosis (Anderson), highlighting evidence for each pathway (Amaral), determining the relation between effectiveness and teamwork (Deneckre), identifying families' experiences (Doody), gathering evidence on the quality of information transfer between primary care and specialist health care (Durbin), examining stigma-related influences on pathways (Gronholm), understanding patient experiences after discharge from hospitals to community health care services (Mutcheler), exploring the effects of implementation of health information technologies in care pathways (Neame), and identifying effective coordination between levels of care and continuity in the transition process (Storm).

Among the primary studies/articles (7 articles), the aims for the three articles *with quantitative data* were as follows: assess personnel perceptions of care processes and examine whether staff consider the differences between pathways with standardized clinical procedures and pathways without such procedures (Biringer), analyse whether care pathways lead to better organization of care processes (Seys), and determine whether the implementation of a pathway improves diagnosis and treatment in conformity with published guidelines (Steinacher).

Of the 4 articles *with qualitative data,* the aims were as follows: understand the contextual influences, mechanisms and outcomes that affect the implementation of online pathways (Akehurst); evaluate how the ‘payment by result’ model works in community mental health, including its impact on the quality of patient care, staff and primary care (Khandaker); assess the extent to which pathways support or inform the creation of elements of frameworks to improve care coordination across the primary hospital care continuum (Van Houdt); and explore the nature of service user involvement in the admission and discharge processes of acute inpatient mental health care (Wright).

The quality of articles was assessed based on the clarity of the research question, the data collection methods used, the type and applicability of the qualitative analysis, the validity of the findings, and the relevance of the results and conclusions. The different study designs made comparison methodologically challenging. As a review of both qualitative and quantitative studies was conducted, a variety of methodological approaches were used. In principle, criteria for validity, reliability and generalizability apply in the assessment of quality for both quantitative and qualitative research; the two types of research are distinguished ontologically and epistemologically by the nature and type of processes characteristic of the research (85).

There are several approaches to determining the validity of research findings. The type of question, which can be misunderstood; leading questions; incomplete data; the use of faulty scales; and the order of items may all bias responses (86). Bias is any influence that distorts the results of a study and undermines its validity (87,88,89). Hagen (90) noted that presenting controversial or emotive items as well as demographic or clinical items at the end of a questionnaire can minimize bias and that several forms of bias may occur when respondents complete a questionnaire. Selection bias may occur during the identification of the study population, and to prevent this form of bias, it is important to have proper inclusion criteria. Bias due to cultural differences, education level and gender can occur both in the interpretation of questions and in the responses. It is important to consider the cultural context and the cultural differences between countries in which care pathways are used. Systematic differences between groups being compared result in called detection bias and must be considered in both qualitative data and quantitative research (88,89).

Validity refers to the degree to which an instrument measures what it is intended to measure (88,89). It can also be evaluated for qualitative studies (89, 91). Credibility is a criterion for evaluating the trustworthiness of qualitative studies and refers to confidence in the truth of the data; credibility is analogous to internal validity in quantitative research. Trustworthiness is essential in qualitative research; the degree of confidence that qualitative researchers have in their data and analyses is assessed using the criteria of credibility, transferability (the extent to which qualitative findings can be transferred to other settings or groups, similar to generalizability), dependability (an evaluation of trustworthiness and reliability), confirmability (trustworthiness and objectivity) and authenticity (whether the qualitative research reflects a range of different realities in its collection, analysis and interpretation of data) (89,91). Granheim and Lundman (92) proposed measures of trustworthiness (credibility, transferability, and dependability) throughout the steps of the research procedure. Shenton (93) included confirmability among the four criteria that may be addressed by qualitative researchers who wish to present convincing work that is academically sound.

One of the selected studies, Rotter et al. (2010), performed a meta-analysis to assess the effect of CPs on professional practice, patient outcomes, length of stay and hospital costs (65).

The essence of meta-analysis is that information from each study in the review is used to develop a common metric, i.e., the effect size. Effect sizes are averaged across the included studies, yielding aggregated information about not only the existence of a relationship between variables but also an estimate of its magnitude (89). Meta-analysis refers to the use of statistical techniques in a systematic review to integrate the results of the included studies (73).

Systematic reviews and meta-analyses have become increasingly important in health care. Clinicians read them to keep up to date with their fields, and systematic reviews are often used as a starting point for developing clinical practice guidelines.

Among the included studies, there were eight RCTs, five controlled clinical trials and two cohort studies. A randomized controlled trial (RCT) features 'a full experimental test of an intervention involving randomized assignment to treatment groups' (94).

However, discrepancies between the results of different systematic reviews examining the same question and between meta-analyses and large trials have shown that the results of meta-analyses can be biased, which may be partly caused by biased results in the trials they include (94).

Qualitative research involves making sense of and recognizing patterns among words to build a meaningful picture without compromising the richness and dimensions of the data. Like quantitative research, qualitative research aims to seek answers to questions of 'how, where, when, who and why'. Unlike quantitative research, which deals primarily with numerical data and their statistical interpretations based on a logical and strictly objective paradigm, qualitative research involves nonnumerical information related to human senses and subjectivity and the interpretation of this information (85,95). Gronholm et al. (74) performed a systematic review that assessed findings from qualitative, quantitative and mixed-methods studies focusing on the relationship between stigma and care pathways among patients with first-episode psychosis and at-risk groups. Data synthesis involved the thematic analysis of qualitative findings, narrative synthesis of quantitative findings, and a meta-synthesis combining these results.

A mixed-method study refers to a study in which both qualitative and quantitative data are collected and analysed to address different but related research questions (96).

Amaral et al. (76) performed a systematic review of pathways to mental health care in Brazil using a narrative synthesis of quantitative and qualitative studies (97).

Mutschler et al. (79) included studies that examined the experiences of mental health patients as they transitioned from an inpatient treatment setting back into their communities. The included studies were empirical papers, both qualitative and quantitative, and the results of each article were qualitatively analysed using the method outlined by Thomas and Harden (96).

The sample size in qualitative interviews is a topic that has been discussed in both qualitative and quantitative research. The guiding concept for determining an adequate sample size in qualitative studies is ‘saturation’, also referred to as ‘information power’. The latter concept indicates that the more information that is relevant to the actual study that members of a sample have, the smaller the number of participants that is needed (91).

1.5 Theoretical perspectives and the implementation of care pathways

1.5.1 Brief history of care pathways

‘Integrated care pathways’ were initially introduced into the health care context in the 1980s in the US, and enthusiasm for care pathways now extends across the world. Care pathways have been promoted as a means to achieve evidence-based practice, clinical governance, continuity of care, patient empowerment, increased efficiency, service re-engineering, role realignment and staff education.

Interest in ‘care pathways’ emerged in the UK during the early 1990s along with the implementation of pilot sites. The assumption was that the implementation of care pathways would improve the quality of care, reduce the length of bed occupancy, improve interprofessional collaboration, increase evidence-based practice, limit costs, and empower patients (98-100). There is, however, only limited evidence that care pathways deliver these outcomes (98-100).

Differences exist in the ways care pathways have developed in the UK and the US (101). In the US, the concept of pathways was originally used as a framework for balancing costs and quality. This was in response to escalating healthcare costs. In the UK, clinical pathways are viewed as a way of achieving a continuum of care across care settings. During the 1990s, clinical pathways in nursing care evolved to become integrated care pathways incorporating all aspects of interprofessional input (102).

1.5.2 Frameworks and models of care pathways

Care pathway implementation is characterized by dual complexity, as the pathway itself represents a complex intervention with multiple interacting components and outcomes (4).

The development and implementation of care pathways are methods that are used to (re)organize care processes and that are employed worldwide for a variety of patient groups (4,16,19).

Thus, care pathways are one of the tools used to structure or design care processes and improve them based on the patient-centred concept. In most countries, the prevalence of pathways is still rather meagre, especially when one considers that the care of 60-80% of patient groups in general hospitals should be suitable for the implementation of care pathways (60).

Healthcare is shifting towards more patient-focused care. The organization of the care process in relation to quality, efficiency, and accessibility will be one of the main areas of interest over the next few years for clinicians, healthcare managers, and policy makers.

When developing pathways for patient groups, health personnel need to consider evidence-based key interventions, interprofessional teamwork, patient involvement and the available resources (58, 102). These complexities make it clear that introducing pathways into an organization and developing, implementing, and evaluating individual pathways is a complex intervention. Pathways are more than only a piece of paper or a file in the patient record (19). Care pathways are *a concept* to introduce into patient-focused care.

Different frameworks and models of care pathways exist. Such frameworks and models of care pathways can be considered methodologies to support the quality and efficiency improvement *process* that are made operational at different aggregation levels; in addition, they can be described as *products* (19).

In 2004, the European Pathway Association (E-P-A) (Fig. 1) was launched. The aim of the E-P-A is to support organizations and individuals in conducting research on bare pathways, with the primary goal of developing, implementing and evaluating care pathways. The other aims are to establish an international network and accompanying international training initiatives to accumulate know-how and foster international cooperation between healthcare researchers, managers and providers from European countries and the wider international community to advise policymakers within the area of healthcare management (103).

A new framework for care pathways is developed based on the results of several international studies through the assessment of team and patient outcomes for various pathologies (18, 19, 104). The objective of the E-P-A framework is to describe components that determine the success or failure of care pathways and assist in developing, evaluating and implementing care pathways to increase the positive outcomes of care pathway implementation. The framework is displayed in Fig. 1 and presented below.

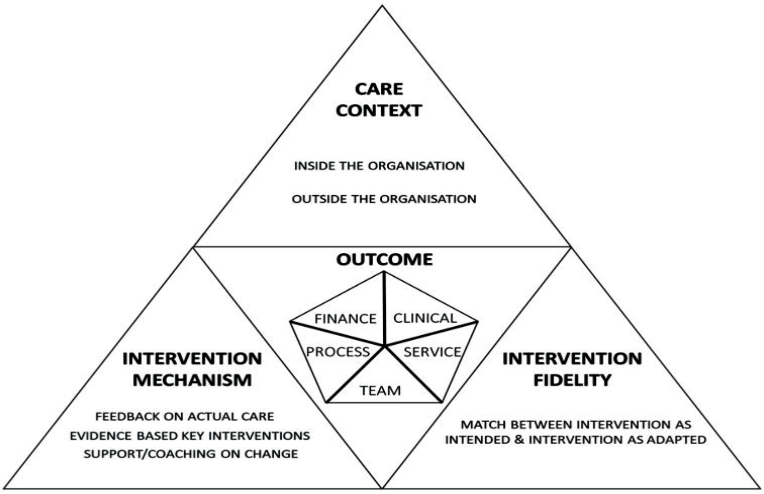

Fig.1. European Pathway Association framework for care pathways.

The new E-P-A framework can help organizations and researchers achieve this goal through its focus on three pillars, i.e., the *care context, intervention mechanism* and *intervention fidelity*, which may determine success or failure of an intervention.

The *care context* represents the context both within and outside the organization. The *intervention mechanism* refers to feedback in the form of actual evidence of care provided through intervention support and coaching on change. *Intervention fidelity* refers to the consistency between the intervention as intended and the intervention as adapted. Regular intern feedback about key interventions for teams is likely to increase fidelity (104). The *outcomes* refer to the consistency between the intervention as intended and practical evaluations of the intervention, i.e., the success or failure of the intervention.

Regarding intervention fidelity, Seys et al. (18) questioned the similarity between the 'intervention as intended' and the 'intervention as adapted', in other words, whether the intervention is implemented exactly as intended.

The *care context* may play an important role in the results achieved from the care pathway implementation, as it influences the care that is delivered (104). Changes in the care context should be considered to understand why and how care pathways work. As mentioned earlier, another tool that can offer more insight in the care context for health professionals is the Care Process Self-Evaluation Tool (CPSET). Rapid feedback increases the success of improvement interventions (82).

Vanhaecht et al. (2012) described a 7-phase method consisting of screening, project management, diagnostic and objectification, development, implementation, evaluation and continuous follow-up phases. However, the method does not guarantee success. The key to success is the collaboration and critical attitudes of the entire multidisciplinary team when implementing pathways (105).

The purpose of care pathways described as *models* is to standardize and establish follow-up procedures for patient-focused care; these *models* are created based on a variety of quality improvement methods and operational research in industry and health care. Two issues are considered important when using or translating these models the level of predictability of the care process and the level of agreement between the members of the interprofessional team (18, 19).

Pathways as processes are described in terms of 'the quality and efficiency improvement *process*'. These care *pathway processes* are means to develop and implement well-organized care and to improve quality and efficiency (106,107). The key ingredients of a complex care pathway intervention are feedback from the organization about the care process, the availability of evidence-based key interventions and outcome indicators, and the continuous quality and efficiency improvement process that takes place within multidisciplinary team (35).

Recent multicentre research has shown that during pathway development, even before the implementation of the pathway, the organization of the *care process* can be improved (19). Over time, teams can improve the quality and efficiency of the care process by analysing the organization and performance of the care process (108-110). Based on the occurrence of bottlenecks, the team can improve the process by using the plan-do-study-act cycle for continuous improvement with respect to patient characteristics and expectations (19).

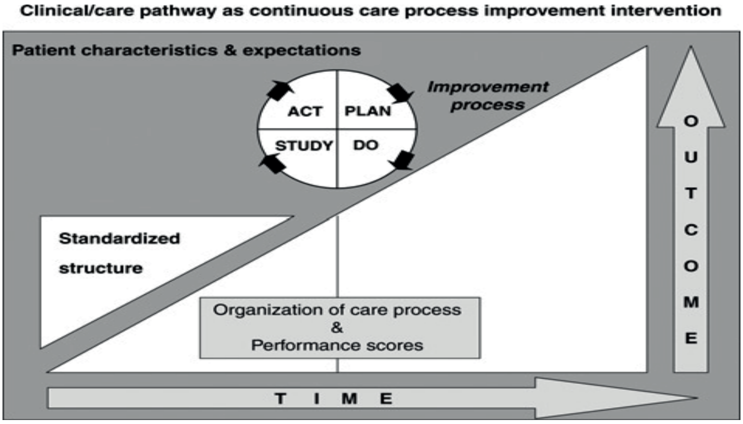

Fig.2. Pathway continuous quality and improvement (K.Vanhaecht et al., 2010).

The pathway as a *product* is also important; however, without the pathway concept, process and model, the product cannot be effectively achieved. Thus, adopting a pathway without translating and adapting it to the specific organization and team could be unsafe and ineffective (26). The pathway *product c*an be a file in the patient record, mostly paper-based, but examples can be found of electronic supported pathways (84,111).

The pathway *product* has four aggregation levels: 1) the *model* pathway, 2) the *operational* pathway, 3) the *assigned* pathway and 4) the *completed* pathway. The patient version of the pathway is a combination of the operational-assigned-completed pathway in patient language (19).

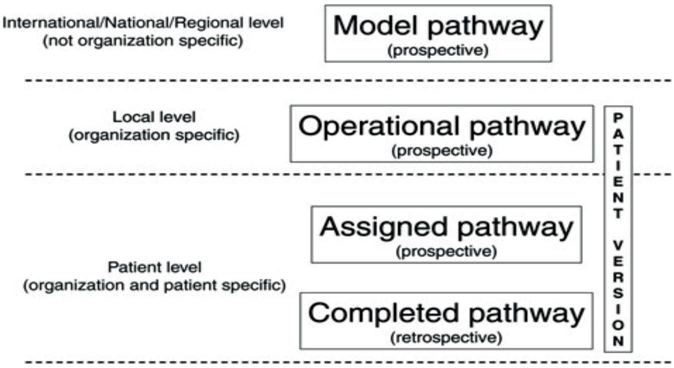

Fig.3. Four aggregation levels of the pathway product (K.Vanhaecht et al., 2010).

The model pathway is the most aggregated level. This pathway is based on the available international and national evidence. It is not organization specific, and many guidelines that also describe the organization of content could be called model pathways.

The operational pathway is the pathway that is developed by a specific organization considering the information from the model pathway and the organization-specific characteristics (available competences and resources). This pathway is organization specific because of the differences between different organizations.

The assigned pathway is the pathway that is used for a specific patient; it is based on the operational pathway and adapted to the needs of a specific individual patient.

The completed pathway is the path that can be reviewed *ex post facto* after the discharge of the patient. The differences observed between the completed pathway and the operational pathway provide information about the variance among and the level of compliance with the key interventions of the path (19). Based on this information, the pathway can be revised and further improved.

The last type of pathway is *the patient version of the pathway* that is used to inform and involve the patient and family about the process of care. Most of the time, *the patient version* is based on the model and operational pathways and can also be used as a communication instrument between the patient, family, and interdisciplinary team (103,112,113).

In addition to the relationship between the professional team and the individual patient, special attention also needs to be given to the patient's family. A patient and family version of the pathway, based on the model and operational pathways, should be an important by-product of care pathways (19).

The goal of care pathways is to introduce and make the patient-focused care *concept* operational (19). Care pathways should be evidence-based as well as up-to-date, i.e., a plan that is enacted and not put away in drawer. There are variations in the content, implementation, and place of service of different pathway plans (103).

Hall and Callaghan (114,115) offered their perspective of how integrated care pathways influence the implementation of the care programme approach and the use of clinical guidelines in mental health care; they found that the care pathway development, clinical engagement, patient involvement and care pathway content are clear factors in ensuring the success of the pathway.

Although 'patient-focused care' can be found in the mission statement of nearly every hospital, rehabilitation centre and primary care organization, it is not always put into practice.

The patient-focused *concept* requires real patient-focused care, which involves a disease-specific orientation and the inclusion of patients as real partners (110,112). Wensing and Elwyn (113) provided an interesting overview of different methods to incorporate patients' views into health care. Although patient satisfaction questionnaires are one of the most widely used tools, more in-depth methods could be employed for pathway projects. Vanhaecht et al. (103) recommended conducting interviews with patients and relatives, performing walkthroughs together with a patient or having a clinician act as a mystery patient to provide useful information for the pathway development team.

1.5.3 A method within the field of continuous quality improvement

The European Psychiatric Association (EPA) found that there is a lack of evidence that is retrievable by a systematic literature search about quality assurance in mental healthcare and that there is a dearth of controlled trials addressing ways to optimize quality assurance in mental healthcare (through structures, processes and outcomes) (104). Internationally, standardized care pathways are increasingly being used as tools to improve the quality of the diagnostics, treatment and follow-up of hospital patients (18, 19). There is some evidence that appropriately developed and implemented pathways can improve the quality and safety of healthcare, but as pathways are complex interventions, one needs to be careful in generalizing results. Vanhacht et al. (2012) concluded that understanding the development changes and implementation process of a particular context is critical to support multidisciplinary teams in their search for excellence. It is recommended that clinicians and managers evaluate each of their individual projects to ensure that patient and organizational outcomes are improved (105). The cultural awareness of (mental) health professionals who address immigrants' mental health needs should be enhanced (116). Gramalia et al. (117) stated that while it is necessary to improve access to mental health services for immigrants, it may be more important to focus on establishing a therapeutic relationship that can be experienced as reliable and trustworthy. Their findings regarding similar pathways to access a community mental health centre for both natives and immigrants seems encouraging.

An understanding of the conditions that influence an improvement in one context is important for spreading this change to other contexts if it proves effective. Ovretveit (118) stated that such an understanding can be advanced by better descriptions of implementations and the contextual factors that are likely important.

A study (119) from Malaysia concluded that before developing any system or any product, there is a need to precisely define the main factor related to it. The development and implementation of care pathways first require the definition of the healthcare quality; as knowledge-based systems, care pathways optimize medical behaviour, and as clinical decision support systems, care pathways play a role in improving healthcare quality.
The development and implementation of care pathways is labour-intensive; thus, resources should be optimally used. As care pathways are continuous quality improvement initiatives, actions should be taken to achieve and increase their sustainability.

1.5.4 Towards a standardized care pathway in Norway

Some hospitals in Norway have recently started developing standardized care pathways for patients in mental health and addiction services (2018/19 The Norwegian Directorate of Health). A main element in the Coordination Reforms in Norway (1,17) that is relevant to the current study is a commitment to ensuring that patients receive optimal healthcare services through cohesive, integrated patient pathways; 24-hour follow-up in the community after discharge from the hospital is recommended. The first national strategy for quality improvement in health care was launched in 1995. Ten years later, the Norwegian Directorate of Health launched a national strategy for quality improvement in the health and social sectors (2005 -2015). The patient’s perspective is central to this strategy (120,121). The recent introduction in 2018-2019 of standardized care pathways in Norway for patients in mental health and addiction services has emphasized the standardization of care pathways as a means of improving the quality of the mental health service.

The organization of health care in Norway poses several challenges in terms of assessment, treatment and follow-up; coordination; the transfer of information; and undesirable variation among patients' experiences (121,122). The introduction of care pathways in oncology (2015) in Norway somatic healthcare has increased the focus on the systematic improvement of care processes as a means of quality improvement. However, it is unclear how well the existing care processes are currently organized (122). Continuity of care is considered by patients and clinicians as an essential feature of good-quality care for those with long-term disorders and has been proposed as a useful criterion for mental health-service evaluation. Burns et al. (123) identified seven independent factors related to continuity in mental health for patients with long-term disorders: experience and relationships, regularity, meeting needs, consolidation, managed transitions, care coordination and supported living.

A recent study in Norway (2017) found a discrepancy between the aspects of continuity that are essential for service users and their experiences of actual practice. The study emphasized that mental health and welfare services should be organized in a way that allows for ongoing collaborative partnerships between service users and professionals (83).

Moreover, as reported previously (31), the establishment of relationships among the three parties involved (patients, inpatient staff, community staff) is of utmost importance in the transition process between inpatient and community mental health care.

The Norwegian Directorate of Health launched 'standardized pathways for progress and

and treatment in mental health care' this year (2019) after some debate (124,125); a care pathway for mental health and drug addiction is shown in Fig. 4.

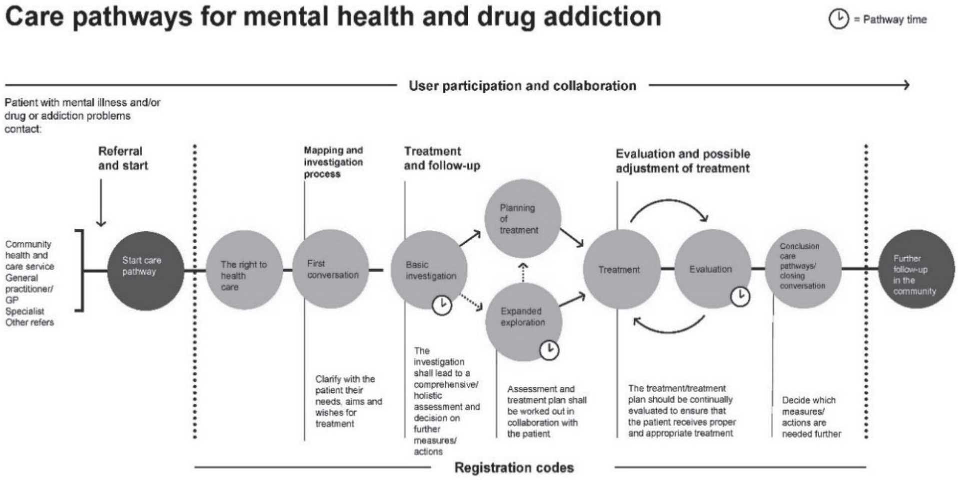

Fig.4 A care pathway for mental health care and drug addiction_ Flow chart.pdf (Translation into English by EWS).

These new care pathways are based on five objectives: 1) increased service use involvement/satisfaction, 2) continuous and coordinated patient pathways, 3) reduced unnecessary waiting times, 4) parity of access to services across the whole country, and 5) better attention to somatic health and lifestyle (130/131). These general objectives are specified as follows. An assessment (treatment) plan must be drawn up and implemented within six weeks, and the patient must receive a copy. Any rejection of treatment must be explained, and a set of 'guidelines for priority setting' should be created that provides indicative deadlines for when to commence assessment for different conditions, e.g., one week for patients with bipolar disorder type 1 who are at an unstable stage (124,125). The type of predictability with respect to assessment and waiting times will require a raising of quality standards compared to those used in current practice. The standardized care pathway in mental health and drug addiction in Norway 2019 has highlighted some important stages in the new standardized pathway, including examination or treatment in the hospital (124). The first stage is examination in a specialized hospital where there is a focus on the goals and needs of the patient and where the next of kin are also sometimes invited to participate. The next step is developing a plan for treatment; patients, treating personnel and perhaps also next of kin participate in this step. The treatment plan can be outlined by giving information to the patient. The coordination of the decided pathway (treatment) is conducted by identifying the health personnel involved in the coordination task. The individual plan is expected to be actively used by the patients and health personnel. In addition, as patients have the right to have a voice in the process, they can ask for different treatment personnel, different treatments, more frequent treatment meetings and so on. The patient's right to evaluate treatment in regular coordination team meetings is also part of the new standardized care pathway (124). Research on the standardization of care processes is needed. Earlier studies in Norway have shown that staff find such changes in intervention practices to improve cooperation between contributors, reduce treatment time, increase the number of operations performed, and improve outcomes for patients (125,126).

A study about a care pathway project in a mental health department in a hospital in Norway also pointed out that relational work takes time, that the strategies that have been used have not supported optimal circumstances for building the empathic relationships necessary for providing care, and that the care pathway concept has to be developed further to devote more space to professional foundations and values (127).

Care pathways vary in content, implementation, and place of service. The content of each step in the pathway of care will be crucial in the future to achieve compliance, quality and efficiency and patient safety (102,110,114,115,128,129).

1.6 Collaborative processes in practice

1.6.1 Patient participation and involvement in mental health care

The concept of patient involvement and participation in is related to other notions, such as empowerment, recovery, shared-decision making, autonomy, and patient-centred care. Promoting patient participation in care has been identified as an international priority by the world Health Organization (130,131).

The patient's own considerations have been identified as an important and empowering element in healthcare reforms. Patients should be given information so that they can understand and act upon it, and support should be customized to their needs so that they are equipped to learn how to manage their health. Activated patients develop their own understanding of health care processes and become engaged in their roles within these processes (9,132).

Tambuyzer et al. (133) proposed a comprehensive model of patient involvement to be used in mental health care. The involvement of mental health care patients in the decision-making process is an ethical requirement. Health care systems worldwide are increasingly emphasizing the value of participatory approaches. There is, however, no consensus on the definition of patient involvement. The literature is particularly inconsistent and lacks clarity (109, 134,135).

In a recent study (2018) on registered nurses' experiences of patient participation in hospital care, the participants described how they made an effort to respect patients' views and accept patients as a part of the care team in order to partner with patients. There were also hindering factors such as patients wanting to take a passive role. Another contributing factor was a lack of teamwork. The nurses, nurses' aides and physicians worked in parallel paths on the ward, but the nurses expressed a wish for all staff members to work together in a team, as they believed this approach would enhance interprofessional understanding and improve patient safety (136).

Another study (2015) confirmed the desire of patients to participate more actively in decision making and provided concrete examples of the factors that patients consider essential for their participation; there are attitudinal obstacles to active participation and the creation of positive conditions by staff in recovery-oriented systems of services (137). Grundy et al. (138) pointed out that user involvement should no longer be regarded as a nebulous concept; they found that ten key criteria that underpin service users' satisfaction with care planning involvement and five criteria that characterize the process of care planning involvement are prioritized by service users.

1.6.2 Shared decision making

Shared decision making (SDM) is increasingly advocated as the preferred model to engage patients in the process of making decisions about a diagnosis, treatment or follow-up when more than one medically reasonable option is available (54,137). People want to be more involved in decisions about their health care. In shared decision making, both healthcare providers and patients are assumed to be experts with valuable information to contribute to the decision-making process (137-140).

SDM is congruent with the values that inform recovery-based practice in mental health, which is advocated by mental health patients, as it promotes empowerment and improves self-management of illness. SDM has also demonstrated positive outcomes in mental health, such as improvements in treatment adherence, patient knowledge, quality of clinical decisions and patient satisfaction (139 - 140). The concept of shared decision making has expanded beyond the physician-patient dyad to include the interprofessional healthcare team (140). This highlights the increased recognition that healthcare delivery involves several different healthcare professions and that patients often consult with different members of the healthcare team. Thus, ideally, all healthcare team members would participate in supporting patients through the decision-making process to reach healthcare choices that are agreed upon by patients and their interprofessional team. The interprofessional approach would necessitate the consideration of interprofessional collaboration among healthcare providers providing decisional support to the patient, as well as consideration of the concept of shared decision making (142).

A systematic review conducted in 2014 concluded that many barriers are potentially modifiable and can be addressed through attitudinal changes at the patient, clinician/healthcare team, and organization levels. The results supported the view that many patients currently cannot participate in SDM rather than choosing not to participate because they do not want to (143).

In another study, patients with serious mental illness and caregivers participated in separate similar focus groups; the study focused on patients in transition between the hospital and community services and examined their roles in treatment decisions. The patients wanted longer visits, to have their stories told, more information about options that was presented simply, to hear from peers about similar experiences, and a greater say in treatment choices. The results suggested that after a decade, SDM may not have achieved the expected penetration into community mental health (144,145).

As Stiggelbout et al. (145) concluded, shared decision making is the preferred approach that is particularly relevant for preference-sensitive decisions. Patients, who are becoming increasingly assertive, prefer this approach. This approach has been advocated for ethical reasons but is still not widely implemented in clinical practice. It is likely to lead to better professional-patient relationships, decisions and outcomes (54,144,145).

1.6.3 Patient empowerment and person-centred care

Patient empowerment is a concept that was introduced to allow patients to transition from a passive role towards playing an active part in the decision-making process about their health and quality of care. The concepts are rooted in social action and associated with community interests and attempts to increase the autonomy, power and influence of oppressed groups, such as poor, working class residents; women; and ethnic minorities. In the research literature, patient empowerment, patient participation and patient-centredness have been popular concepts for quite some time. Despite the popularity of these three concepts, the existing scientific literature offers no univocal definitions for these concepts (145).

Castro et al. (146) concluded in a recent review that patient empowerment is a much broader concept than just patient participation and patient-centeredness. However, within mental health care, 'person-centeredness' has been generally interpreted to convey a holistic approach with an 'attitude of respect for the individual and his or her unique experience and needs' (147). More recently, the psychiatric and mental health literature has appeared to have 'rediscovered' the concept of person-centeredness; in the research on 'psychiatry for the person', it has been stated that the mental health care system has shifted towards a person-centred model of service provision that promotes social integration, empowerment, hope and vision. By emphasizing the social and interpersonal factors, along with the biological factors contributing to mental illness, community-based mental health services have been found to empower people with severe mental illness and promote their independent living and integration in the community (147,148).

1.7 Aims of the thesis

Based on the mixed findings of the previous care pathway research, this thesis aimed to explore care pathways in mental health practice. An overall aim was to provide relevant knowledge on the transition process between intermediate/acute institutions and community health services.

This thesis is based on data from two studies. Study 1 (presented in Papers I and II) was a study with a qualitative design that used a descriptive approach with focus group interviews. The experiences of health personnel from two psychiatric hospital centres and seven different communities revealed important factors related to the content of care pathways for patient transitions between hospitals and community mental health services.

Study 2 (presented in Paper III) was a study with a quality design that used a descriptive approach with focus group interviews. The experiences of former mental health patients who had been hospitalized revealed important factors related to the content of care pathways for patient transitions between the hospital and community.

The following research questions were investigated:

a) What are the psychiatric obstacles to and success factors for patients' pathways in the transition between community health services and intermediate psychiatric units?

b) How do community psychiatric health teams cooperate and coordinate patient care pathways in the transition from community health services to intermediate/acute psychiatric units?

c) What are important factors for patient participation and involvement in mental health care pathways between the hospital and community?

d) What are the factors of care pathways that can improve quality and knowledge in the transition between psychiatric units and community health services?

2.0 METHODS

2.1 Study 1: Health personnel experiences of care pathways in the patient transition between inpatient and community mental health services (Papers I and II)

2.1.1 Design

A qualitative design with a descriptive approach was chosen to reveal important factors of care pathways for mental health patients (88,89).

Seven focus groups were conducted with a total of 18 informants recruited from two psychiatric hospital centres. In addition, four focus group interviews with 12 informants from seven different communities were conducted. The interviews were analysed thematically. Data were analysed to identify condensed meaningful units, categories (sub-themes) and themes. An interpretive, descriptive approach was chosen. This approach allowed the generation of new insights to help shape the application of the qualitative evidence to practice. Concepts related to the research procedure and measures to achieve trustworthiness, including credibility, dependability and transferability, were used throughout the research procedures (92,93).

The focus group sessions were carefully planned and discussed to take advantage of the group dynamics to access rich information. Prior to the focus group sessions, we discussed in great depth which questions to ask. We studied the comprehensive summaries of phenomena and events described in the focus group sessions to detect major categories, themes, and patterns using thematic analysis (149 - 151).

2.1.2 Participants, selection and demographics

A total of 18 experienced health personnel, expert nurses in psychiatry and one psychiatrist from two psychiatric centres, including two district psychiatric hospital centre (DPC) ambulant teams, participated in seven focus groups between 2013 and 2014. The two decentralized specialist healthcare services, which were intermediate care institutions (DPCs), shared the primary responsibility for the mental healthcare of adults in a given geographical area with approximately 72 500 inhabitants >18 years old by January 2015 (Statistics Norway). The two DPCs had similar organizational structures concerning the pathological severity of the patients as well as the number of staffs. Both DPCs offered outpatient treatment and ambulant teams as well as access to psychiatrists, psychiatric nurses, psychologists, occupational therapists and physiotherapists.

Twelve health employees from seven community mental health care settings (one urban and six rural) were interviewed in four focus groups (2015-2016). The leaders in the community health care settings identified experienced mental health personnel for the focus groups. All the leaders had positive views of the study and acknowledged the need for focusing on pathways of care, especially obstacles that could prevent smooth transitions. They assisted the researchers in identifying participants who would offer comprehensive and unbiased information. All of our participants were involved in the practical coordination of pathways of care. The inclusion criteria were >5 years of experience in mental health care and worked in an at least 3/4-time position.

All participants were female with more than 10 years of experience in mental health. Most health personnel in mental health in Norway are women. The study included nine nurses, two carers, and one social worker, all specialized in mental health care.

2.1.3 Procedure and ethics

The leaders of the DPCs and community services selected health personnel for the focus groups. Two researchers informed the selected participants and coordinated the focus groups. Two psychiatric nurses assisted in the focus group interviews, matching statements to specific informants. All informants gave written consent to participate in the study. The study was approved by the Norwegian Centre for Research Data (NSD, project no. 51960) with no additional approval required for ethical clearance. All phases of the study were conducted according to the Helsinki Declaration (152) and ethical principles in research. The data were transcribed and anonymized accordingly. Written consent was obtained from all participants.

2.1.4 Focus group interviews

We used a semi-structured interview guide. The participants 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 discussions according to the following topics: planning; collaboration between patients 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. The facilitator guided the focus group discussions according to pre-prepared questions and topics to be covered, interpreted the responses, asked follow-up questions and discussed the interpretations with the participants. An assistant moderator contributed by regularly summarizing and following up on key information revealed in the group discussions [149 -151, 153). At the end of the focus groups, 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 between 90 and 120 minutes.

2.1.5 Data analysis

The seven focus group discussions with a total of 18 informants who were recruited from two psychiatric hospital centres were transcribed and analysed through ethnographic content analysis using template text analysis. A codebook was developed based on the variables identified by our research team at the beginning of the study as being theoretically relevant to the research questions and the literature. All transcripts were coded accordingly.

The two researchers that conducted the focus groups also performed the analysis. Both had access to all material. When disagreements arose or there was lack of understanding of the summaries, the full text was consulted to achieve consensus. Common meanings were identified, and a degree of agreement on the text was reached. Relationships or patterns between categories were found and supported with the material. We then looked for patterns in the informants' expression of relationships between the themes. Finally, the transcribed content was analysed for meaningful units related to barriers and success factors. As in conventional procedures used in quality research, questions were asked until saturation of themes was reached.

The four focus group interviews with 12 informants from seven different community health services were transcribed and analysed through thematic text analysis in six phases: familiarizing ourselves with the data, coding, searching for themes, reviewing the themes, defining and naming the themes, and writing up [154-157). A codebook was developed based on the 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 (92) proposed measures of trustworthiness (credibility, dependability, and transferability) were applied throughout the steps of the research procedure. The analysis of group-level data involved scrutinizing the themes, interactions, and sequences within and between groups. Each informant was allocated a code letter to be recognized in the results section. Two letters are provided when more than one informant shared the same views, either by nodding or repeating words. We performed an iterative analysis in a systematic, repetitive, and recursive process.

2.2 Study 2: Patient perspectives on care pathways and informed shared decision making in the transition between psychiatric hospitals and the community (Paper III)

2.2.1 Design

A qualitative research design with a descriptive approach was used to reveal important factors of care pathways for former mental health patients (88,89). Three focus group interviews were conducted with a total of ten informants, three men and seven women, with a mean age of 40 years from (five) different communities. The interviews were transcribed and analysed thematically, and the themes described what patients perceived as facilitators or barriers in the transition phase (149-151). In Norway, mental health community services are provided by general practitioners (GPs) and mental health nurses/social workers who collaborate in providing somatic health services. In addition, these health care providers are expected to cooperate with mental health specialized service providers in hospitals. The hospital mental health service providers can advise community health service providers on treatment, but community service providers make their own decisions regarding care in terms of how often patients should be visited, what interventions or resources are provided for this from their budgets and subsequent further hospitalization or visits from ambulant teams.

2.2.2 Participants, selection and demographics

The leaders of community mental health volunteer organizations and a rural mental health activity centre identified experienced former mental health patients who had been hospitalized to participate in the study.

Ten former patients from five communities who had previously experienced the transition into and out of inpatient services (DPCs) were interviewed and participated in three focus groups in 2017. Three participants were attending a rural mental health activity centre at the time of the study, and seven had mental health peer support roles in the communities. All informants were former patients in DPCs and had more than 10 years of lived experience in accessing mental health services and undergoing transition processes. They were well positioned to reflect upon what seemed to work/not work in these transition processes. The participants were seven women and three men. Due to the richness of the informants' own quotes, 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 achieve the aim of this study (91).

2.2.3 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 the study did not require full REC approval (REC 2018/1181) (Presentation assessment). All phases of the study were conducted according to the Helsinki Declaration (152) and ethical principles in research. The data were transcribed and anonymized accordingly. Written, informed consent was obtained from all informants.

2.2.4 Focus group interviews

We used a semi-structured interview guide in the focus group interviews that was developed with university and health care representatives. The informants were asked to describe their views on their experiences of care pathway transitions between DPCs and community mental health services. The interviewer guided the focus group discussions according to the written set of topics: planning; cooperation between patients 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 on key information revealed in the group discussions (149 - 152,154). At the end of the focus groups, 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.

2.2.5 Data analysis

Data analysis process

The interviews were transcribed and analysed through thematic text analysis in six phases: familiarizing ourselves with the data, coding, searching for themes, reviewing the themes, defining and naming the themes, and writing up (154-157). A codebook was developed based on the 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 (92) proposed measures of trustworthiness (credibility, dependability, and transferability) were applied throughout the steps of the research procedure. Each informant was allocated a code letter to be recognized in the results section. Two letters are provided when more than one informant shared the same views, either by nodding or repeating words.

The steps in analysis included familiarization with the content of the data, rereading with an awareness of the initial conceptualizations 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, we conducted continuous comparisons to identify similarities and differences in different parts of the data.

Through the thematic text analysis, we ultimately identified four main themes. The four themes emerged from the categorical content analysis conducted according to an analysis model previously reported by Ilanit Hasson-Ohayon et al. (158), 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 the salient excerpts that typified the participant statements.

3.0 SUMMARY OF THE RESULTS

3.1 Paper I (Study 1)

Barriers and success factors in clinical pathways: the transition process between psychiatric inpatient care and community care.

(Sather EW, Svindseth MF, Sorthe I, Hagfonn G, Iversen VC. (2016) Eur J Pers Cent Healthc.)

This study explores the experiences of health personnel in psychiatric hospital centres (DPCs) of care pathways in patient transitions between inpatient and community mental health services. The aim was to identify (a) the factors that may obstruct the intended clinical care plan as devised by DPSs for implementation by community services and (b) the strategies that support the effective delivery of high-quality care. In addition, the scope and limitations of care pathways in monitoring patient-care management in a selected group during a specified time period were examined.

Three main themes emerged: a) coordination, b) clinical care and c) ethics. The main barriers of the clinical pathway identified were communication errors, a lack of treatment compliance due to disagreement about treatment and a lack of competence in some aspects of the treatment pathway, especially in community services, due to a lack of personnel continuity and mental health nurses as well as limited working hours for ambulant teams. The main success factors were adequate direct communication and proper documentation systems between health personnel, patient participation in future plans, and the working hours of ambulant teams.

The study suggests that clinical pathways are useful for securing key objectives at the interface between hospital and community-based psychiatric care. Improved information sharing in/between all care systems is imperative to strengthen patients' participation in decision making, ownership of the care plan and improve adherence to treatment.

3.2 Paper II (Study 2)

Care pathways in transition between district psychiatric hospital centres (DPCs) and community mental health services.

(Sather EW, Svindseth MF, Crawford P, Iversen VC. (2018). Health Sci Rep.)

This study explored community health personnel experiences of care pathways in the patient transition between psychiatric hospital (inpatient) care and community mental health services.

The apparent goal of care pathways is to achieve optimal efficiency and improve the quality of care as prioritized in health strategies in Norway. Thus, the current study endeavoured to contribute to this area of research by exploring community health personnel experiences and providing an understanding of CPs in the patient transition between psychiatric hospital (inpatient) care and community mental health services.

Two main themes were identified: integrated care and patient activation. The participants shared their experiences related to factors that could support smooth care pathways in mental health. Six promoting factors were identified for successful patient transitions: opportunities for information sharing, the implementation of systematic plans, the use of e-messages, the provision of around-the-clock care, the designation of one responsible health person in each system for each patient, and the involvement of patients and their families. The following barriers were all found to impede the patient transition between levels of care: the lack of a single responsible person at each health care level, an insufficient number of meetings, an absence of systematic plans, difficulties in identifying the appropriate staff at different levels, delays in information sharing, and the complexity of welfare systems that negatively affected patient dignity.

The mapping of responsible personnel ensures appropriate follow-up based on key findings at the point of transition between services in terms of cooperation, information, and documentation. To ease the transition for patients leaving around-the-clock treatment and care and re-entering the community, it is important to ensure proper follow-up at the appropriate time. If communication fails, people in need of re-admission might not be identified. The appointment of a single responsible person (and system) and clarified procedures should be implemented at each stage of care pathways to avoid liability and establish transparent systems that can be easily monitored by health personnel and patients. A single responsible person could be responsible for coordinating services as well as liaising between social and health systems and patients.

Both digital and telephonic sharing of information and communication should be implemented and established before patient admission to a hospital-based service and before and after discharge back to the community. To ensure effective information sharing, all parties should have the name and phone number of a responsible coordinator in each health care and social care system to allow easy access to all parties. Regular meetings should be scheduled in which mental health personnel can share and discuss key information with the social care system to avoid the long delays that extend inpatient status and prevent a satisfactory transition to the community setting.

3.3 Paper III (Study 3)

Patient' perspectives of care pathways and informed shared decision making in the transition between psychiatric hospitalization and the community.

(Sather EW, Iversen VC, Svindseth MF, Crawford P, Vasset F. (2019). J Eval Clin Pract.)

This study explored former patients' views of pathways in the transition between district hospital centres (DPSs) and community mental health services. These former patients from five communities had previously experienced transitions into and out of inpatient services (DPSs).

Through the thematic text analysis and categorical content analysis, we ultimately identified four main themes, which are presented here. The participants' interview responses indicated their positions along a continuum of the individual themes or their dynamic oscillation between the themes. Four aspects of care pathways in the transition between DPCs and community mental-health services emerged from the analysis. The informants shared their experiences of factors that promoted or prevented successful care pathways in mental health.

The need for patient participation in processes, the provision of enough information and documented plans at the appropriates times in care pathways, and collaboration with the appropriate professionals with the necessary abilities to make planned activities happen were reported to be important. There was a strong emphasis on having a holistic understanding of patients' health needs and meeting these needs through full sharing of information in shared decision making. 'Informed shared-decision making' could better describe the preferred approach to achieving smooth pathways of care. Additionally, the importance of 24-hour ambulant teams in the community was emphasized, and it was recommended that the community should include former patients as consultants to ensure that patients' experiences, voices and opinions are heard.

Person-centred care seemed to be reflected in most of the participants' statements concerning improving pathways of care. The participants suggested that patients should be an active part of 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. Person-centred care was recommended as an approach to prevent patient humiliation in mental health care.

The factors promoting smooth pathways in mental health care can be summarized as follows based on the study findings: a) the desire of patients to participate in the transition process; b) the need to take into account patients’ views and values; c) the importance of providing patients with enough information and documented plans at the appropriate time; and d) the importance of collaboration between mental health and other professionals to guarantee that planned activities meet patients’ needs. The concept of shared-decision making does not adequately describe what the study informants wanted to see in care pathways in care transitions. Our informants emphasized the need for full sharing of information to make the appropriate shared decisions; thus, ‘informed shared-decision making’ could better describe their preferred approach to achieving smooth pathways of care.

4.0 DISCUSSION

4.1 Discussion of the findings

4.1.1 Variability in health personnel and patient experiences of care pathways

The informants in the present studies were recruited from hospitals and communities and from the population with the most experience with care pathways, namely, patients. The qualitative statements from health personnel mainly showed agreement on various topics that they found important to provide smooth pathways.

4.1.2. DPC healthcare professionals' views

The main barriers to the success of care pathways that were identified were communication errors, a lack of treatment compliance due to disagreement on treatment, and a lack of competence. The main success factors were adequate direct communication and proper documentation systems between health personnel, patient participation in plans, and the working hours of ambulant teams. The appropriate tools for information sharing should be identified and used across all systems that need to share vital information and documentation regarding care pathways. Interprofessional cooperation and systems to communicate efficiently with the decisionmakers involved in patients' economic situations, housing and work facilities were perceived as crucial. The informants in our study reported problems in community services to include severe workload pressure, especially for mental health service providers, and the lack of preparation of patients for discharge. The informants wanted more help in under-resourced community settings, particularly on evenings and weekends. A short-term analysis could suggest that this approach would lead to increased costs to the hospital, but it is possible that a long-term cost-effective analysis would reveal a cost decrease due to fewer readmissions to hospitals as well as patients functioning at higher levels in their homes.

4.1.3 Community healthcare professionals' views

The findings from the community informants pointed to integrated care and patient activation as main topics. The informants shared their experiences with factors that can affect smooth care pathways in mental health. Six promoting factors were identified for successful patient transitions: opportunities for information sharing, the implementation of systematic plans, the use of e-messages, around-the-clock care, the designation of one responsible health person in each system for each patient, and the involvement of patients and their families. The following barriers were all found to impede patients' transitions between levels of care: the lack of a single responsible person at each health care level, an insufficient number of meetings, an absence of systematic plans, difficulties in identifying the appropriate staff at different levels, delays in information sharing, and the complexity of welfare systems negatively affecting patient dignity. A setting with the appointment of a single responsible person (and system) and clarified procedures should be implemented at each stage of care pathways to avoid liability and to provide transparent systems that can be easily monitored by health personnel and patients. A single responsible person could be responsible for coordinating services as well as liaising between social and health systems and patients. Most ambulant teams are managed by and provide work for different organizations at different health levels. Ambulant teams could strengthen patient loyalty and increase cooperation between health levels.

4.1.4 Former patients' views of care pathways - No patient influence in decision making in care pathways

Encouragingly, all patient informants agreed on what is important to contribute to smooth pathways. To achieve treatment compliance and optimal cooperation between health personnel and patients, we need to take patients' views seriously. Four main themes were identified: 1) patient participation, activation, and empowerment versus paternalism and institutionalization, 2) patient-centred care versus care interpreted as humiliation, 3) interprofessional collaboration or teamwork versus unsafe patient pathways in mental health services, and 4) sustainable integrated care versus fragmented, non-collaborative care.

In the flowchart in Fig. 4 (124,125) from the Directorate of Health in Norway, it seems appropriate to include shared decisions in the first interview and allow shared decisions to be included in the whole chart. Patients' views of their own health and future treatment must be heard from the start to gain treatment compliance. Our patients reported that the transition from the hospital to the community often was perceived as a struggle because of their limited control of and participation in the planning process. During a long or short stay in a mental health institution, a patient should not be separated from life in the community. The patients highlighted the importance of activation and participation and reported that their negative experiences characterized by a lack of involvement and meaningful engagement. Indeed, a holistic approach is necessary to decrease the number and length of admissions; that is, the patient's full and diverse life should be considered, and the view of the patient should not simply be limited to his or her status of having mental health issues (159).
In reporting a lack of control and mutual decision making in the existing care pathways in the transition between services, our respondents emphasized the role of information in such transitions. Prior meaningful discussion between patients and health personnel about the transition from one service to another was considered of paramount importance. Respondents reported a lack of interprofessional collaboration between teams working in mental health, somatic health, and user-led organizations.

Shared decision making can naturally be emphasized in meetings about treatment plans as well as when an individual plan is sketched. Patients also felt they had too little time to read through the discharge papers, so efforts should be made to prepare discharge papers the day before discharge to allow time for the patient to review them before it is time for the patient to leave the hospital.

4.1.5 Summary of the content of care pathways according to the different informants

All parties agreed on the importance of sustainable integrated care, which was understood to occur when health professionals consider all health conditions at the same time instead of adopting a fragmented disease-specific focus (31). Patient participation and shared decision making were rated as very important, and improved information sharing within and between all care systems was viewed as imperative to strengthen patients' participation in decision making and their ownership of care plans as well as to improve compliance. The importance and value for the patient of maintaining therapeutic links at the DPC while in the early stages of the transition back into the community was strongly emphasized. Health personnel indicated that discrepancies may occur between the views of health personnel and patients regarding some of the decisions, but they also discussed how to solve such situations. A lack of cognitive function, whether permanent or temporary, could cause disagreements about the planned treatment, both at the hospital and in the community. When such disagreement happens, compliance can be promoted by respectfully giving patients complete information about why health personnel must act in certain ways (160). The planning of next steps, whether for hospital treatment or community treatment, was identified as an important discussion topic in the transition phase. All informants agreed that collaboration and inter-professionality would offer the best chance of reducing patients' mental health issues and would provide the appropriate documented plans for a better daily life for each patient.

The informants from the hospital seemed to be more oriented towards clinical symptoms than were the informants from the community and the patients. Their focus on symptoms is understandable, given that working to reduce mental health symptoms is an important task of hospitals. The community health personnel informants were more concerned with patients' daily functioning and the planning of activities suitable for each patient. The focus on patients' daily lives is understandable because they see and visit patients in their homes and thus view their work to be more about reducing difficulties and promoting treatment compliance from a broader perspective compared to the work of hospital staff. The former patients seemed to rate the right to receive the respect they deserved and to not be subjected to humiliation, as well as the ability to receive practical help when needed from other parts of the system, such as through talking to NAV employees, as the most important factors. One important point was the patients' statements on the importance of non-fragmented care, which highlighted the need for a broader perspective on the implementation and content of pathways of care in mental health. According to the patients, cooperation with next of kin was also lacking most of the time, and they seemed less occupied with confidentiality in the field of mental health care and more occupied with sharing information with those involved in the treatment. This might imply that health personnel could focus more on seeking permission to share information with specific personnel and next of kin. Patients also reported a need for the community to engage a former patient to assist patients in the care pathway system as well as with life in the community. Our patients were also worried about workload pressure in the community and indicated the need for around-the-clock service in the community.

4.1.6 General discussion

The pathways of care outlined by health authorities in Norway have been described on a point-to-point basis, i.e., which actions should be taken within certain time limits, who should participate in decision-making processes, and a clear beginning and a end of the responsibilities of each health level. Although the importance of cooperation between levels were reported to be important, the beginning and end points of each pathway could be a very large barrier to cooperation between levels in mental health care.

The findings in this thesis have expanded the existing knowledge on care pathways. The formal pathway proposed by the Directorate of Health (2018/2019) could benefit from the incorporation of content that should be present in the description of such a pathway. Each paper in this thesis presents experiences of patients and health personnel, contributing to new knowledge about care pathways, especially concerning the content of each stage in the care pathway. The overview of the present literature revealed that different care pathways have been defined based on very strict timelines, as mentioned above (124,125).

Care pathway plans should either be expanded to also include the transition from one care level to another, or the transition process should have its own transition pathway plan. The latter solution could result in more discussions about who is responsible for what and could take valuable time and resources away from providing what is best for patients. Hopefully, future research will reveal which model is best for developing pathways that best suit each group of patients.

Given the nature of mental health, collaboration and coordination between health levels should probably be described in a mutual care pathway that includes tasks for both hospital units and community mental health services and that specifies which tasks belong to which level in the transition process.

As guidelines of pathways of care could be perceived as lacking an emphasis on individual patients' needs and wishes for their own lives, discussions and consideration of patients' values and views could transform a rather generalized pathway into a pathway tailored to each patient. A positive point in the guidelines (Fig. 4) is that they recommend a plan for processes and treatment and that they should be planned in partnership with the patient.

It is also recommended that treatment plans be continuously evaluated and eventually adjusted (124/125). However, there are some concerns in the clinical area: will care pathways lead to less patient-centred practice that is defined by the patient's symptoms, worries and expectations and instead a focus only on the symptoms of interest that fit with the pathway guidelines (126)?

Part of the rationale used to justify the introduction of care pathways is that patients within the same diagnostic categories have received dissimilar treatments from specialist services. This makes sense because we know from treatment research that many different approaches may be equally effective (103,161).

The recommendation by Vanhaecht et al. (103) provided a starting point for debate and the sharing of experience and research to better use pathways to reduce adverse events and improve outcomes. Ovretveit (161, 162), in response to the paper by Vanhaechts et al. (103), asked, 'Is there a future for care pathways?' The paper suggested that there is a future in which patients will experience more benefits if five actions are taken: 1) make pathways more evidence-based; 2) focus on disease-specific care; 3) invest in real teamwork; 4) develop technical support for pathways; and 5) see patients as partners. Øvretveit (162) commented that these five actions should not be presented only as an answer to 'sustain the quality and efficiency of pathways and to keep the already implemented pathways alive'; instead, the purpose of the paper should be clearer, and the paper should focus more on how to develop the potential of pathways to benefit patients rather than only how to sustain them. In addition, regarding 'making pathways more evidence-based', two aspects were highlighted: first, the content of the pathway and second, research into the effectiveness of different types of pathways and especially implementation research. Even when pathways that cross functional and departmental boundaries are well made, they are probably not sufficiently developed, and the greatest risk exists for patients who are situated 'in between'. Pathways are one solution to safety problems and can improve extended care episodes as part of preventing unnecessary hospitalization (10,77,79).

Shared decision making (SDM) is an effective health communication model designed to facilitate patient engagement in treatment decision making. In mental health, SDM has been applied and evaluated in relation to medication decision making but less so regarding its contribution to personal recovery and rehabilitation in mental health settings. A recent study (163) assessed the effect of SDM in choosing community psychiatric rehabilitation services before discharge from psychiatric hospitalization. Informants in the intervention cohort reported greater engagement and knowledge after choosing rehabilitation services and using services at the 6-to-12-month follow-up than those receiving standard care.

In a literature review in the UK (114, 115), various approaches to managing care pathways in adult mental health were compared. The authors found that progress has been made to ensure therapeutic individualism and choice for service users in relation to care pathway content.

The importance of shared decision making is of utmost importance. Without ownership in decision making, patients will probably be less treatment compliant. However, Grim et al. (2019) described obstacles to legitimizing patient knowledge, including relational issues that patients highlighted: being independent, often being dismissed and choosing to edit their testimonies. Health providers typically described workflow issues, patients' insufficient decision-making competence and patients' vulnerability to stress factors. The findings suggested that greater epistemic justice might be achieved by SDM processes in which patients are engaged as a full partner in collaboration in various activities related to their care (164).

The factors promoting smooth pathways in mental health care can be summarized as follows based on the study findings: a) the desire of patients to participate in the transition process; b) the need to take into account patients' views and values; c) the importance of providing patients with enough information and documented plans at the appropriate time; and d) the importance of collaboration between mental health and other professionals to guarantee that planned activities meet patients' needs. The concept of shared-decision making does not adequately describe what the study informants wanted to see in care pathways in care transitions. Our informants emphasized the need for full sharing of information to make the appropriate shared decisions; thus, 'informed shared-decision making' could better describe their preferred approach to achieving smooth pathways of care.

4.2 Discussion of methods

4.2.1 Studies 1 and 2: Qualitative studies

The trustworthiness of research depends on maintaining quality throughout all stages of the research process, and a reflective attitude is essential. It is crucial to be aware of the researcher's influence during all steps of the research process. According to Malterud (2001), such awareness is an aspect of reflexivity (165).

Because of the richness of the informants' narratives, their experiences, and their ability to identify factors of successful transitions, it was determined that the focus groups provided enough information power to achieve the aims of the study (91).

Although the number of informants was rather small, especially in the former patient group, the findings seem to be supported by the review studies described in section 1.4.3. Findings cannot be generalized from qualitative studies, but the described content can be used in future discussions focused on the content of care pathways, both in the field of mental health and for politicians in charge of making decisions.

A descriptive qualitative design was chosen for the studies. The informants were from both hospitals and community services, and they shared their experiences related to factors that promote or prevent successful care pathways in mental health. The analysis of group-level data involved scrutinizing the themes, interactions, and sequences within and between groups.

In the studies, qualitative content analysis and thematic analysis were used, which are two commonly used approaches in health research data analysis. There are differences between the two that have not been clearly specified because it seems difficult to choose between them. However, Vaismoradi et al. (2013) described and discussed these boundaries and presented some implications to improve the consistency in the purposes of related studies and methods of data analyses. The authors concluded that despite many similarities between the approaches, including cutting across data and searching for pattern and themes, their main differences lie in the opportunity for the quantification of data (157).

Thematic and content analyses are qualitative methods that serve different research purposes. Thematic analysis allows the interpretation of participants' meanings, while content analysis involves the direct representation of participants' responses. These methods provide two ways of understanding meanings and experiences and provide important knowledge in the mental health context (166).

In the text analysis in the last paper on the study with former patients, four themes emerged from the categorical content analysis. These themes were presented, and the participants' interview responses indicated their positions along a continuum of the individual themes or their dynamic oscillation between the themes. This is in accordance with an analysis model previously reported by Hasson-Ohayon et al. (158).

Validity refers to the degree to which an instrument measures what is intended to measure (92). It has been suggested that measures of trustworthiness (credibility, transferability, and dependability) should be used throughout the research procedure. Confirmability is addressed by qualitative researchers wishing to present convincing work that is academically sound (93).

The findings of the qualitative studies are non-generalizable but offer valuable insights and understanding about care pathways in the transition between DPSs and community mental health services. Such findings can assist in tailoring the organization of care pathways to enhance patient experiences of mental health care transfers.

It is acknowledged that the focus of this paper has been on the health planning system in a region in Norway, and different findings may emerge from other regions in Norway and from other territories. Our findings indicate that further, more comparative research could test and build upon these initial findings. Future longitudinal research is recommended to investigate trends in patient involvement and patient participation in the development of enhanced, well-organized transitions. Additionally, the best practices for shared interprofessional work according to standards for pathways of care should be determined.

5.0 CONCLUSIONS

5.1 Implications for practice

Care pathways are useful for establishing key objectives in the interface between hospitals and community-based mental health care. To achieve sustainable integrated care, pathways of care should also describe content of the transitional phase in and out of hospitals and community services. Informed shared decision making and shared information between all parties in care pathways is key to emphasizing patient participation. Respectful communication should be emphasized to avoid patient humiliation that could undermine treatment compliance. Around-the-clock ambulant teams in the community are important to avoid a sense of being ‘lost’ after discharge from the hospital and for the continuity of care. Activate user-led patient organizations and/or the involvement of next of kin in the transition process could be helpful to former patients in the community. For those already in the transition process, clearly documented plans should be provided to support patients in contacting house-seeking, employment-seeking and welfare offices. Systems and procedures should be developed to ensure clear responsibility and transparency at each stage of pathways of care.

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ARTICLE

Barriers and success factors in clinical pathways: transition process between psychiatric inpatient care and community care

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Abstract

Rationale, aims and objectives: This study examines the scope and limitations of clinical pathways to monitor patient-care management of a selected patient group during a specified time period. We aimed to identify (a) the factors that may obstruct the intended clinical care plan as devised by psychiatric hospital centres for implementation by community services and (b) the strategies which support the effective delivery of high quality care.

Method: A qualitative design incorporating a descriptive approach was chosen. Seven focus groups with a total of 18 informants were convened. Data were analysed to identify condensed meaningful units, categories (sub-theme) and themes.

Results: Three main themes emerged; Coordination, Clinical Care and Ethics. The main barriers were communication errors, lack of adherence to treatment due to disagreement on treatment and lack of competence. The main success factors were adequate direct communication and proper documentation systems between health personnel, patient participation in future plans and working hours of ambulant teams.

Conclusions: This study suggests that clinical pathways are useful for securing key objectives at the interface between hospital and community-based psychiatric care. Improved information sharing in/between all care systems is imperative in order to strengthen patients' participation in decision-making, ownership of the care plan and improve adherence to treatment.

Keywords

Adherence to treatment, clinical and digital communication, clinical pathways, district psychiatric hospital centres, effective service delivery, evidence-based medicine, focus groups, multi-disciplinary teamwork, patients, patient empowerment, patient participation, person-centered healthcare, psychiatry, quality of care, treatment satisfaction

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Introduction

The term 'clinical pathway' is understood in many different ways [1]. It was first employed in 1985 by Zander [2] at the New England Medical Centre and the term is now internationally employed in almost all service delivery settings and models of healthcare management [3,4]. The definitions used for clinical pathways and the purposes they are intended to serve have generated some confusion. For instance, there is still no single, widely accepted definition of a clinical pathway [5,6].

For the purposes of the present study, a clinical pathway is taken to be a method for managing patient-care for a circumscribed group of patients during a specific transition between health systems. Generally, clinical care pathways are grounded in evidence-based medicine (EBM) guidelines and best practice, taking into account patients' expectations. Essential elements in this care process are open communication and well organised and delegated coordinating roles for multi-disciplinary care team service delivery, so that these accord with agreements reached with patients and relatives [7].

Interest in care pathways emerged in the UK during the early 1990s and led to the implementation of pilot sites. The assumption was that implementation of care pathways would improve quality of care, reduce length of bed occupancy, improve multi-disciplinary collaboration, increase evidence-based practice, limit costs and empower patients [8-10]. There is, however, only limited evidence that care pathways deliver these outcomes [10,11].

Differences exist in the ways clinical pathways have been developed in the UK and the US [12]. In the latter, the concept of clinical pathways was originally used as a framework for balancing costs and quality in response to escalating healthcare costs. In the UK, clinical pathways are viewed as a way of achieving a continuum of care across care settings. During the 1990s, clinical pathways in nursing care evolved to become integrated care pathways, incorporating all aspects of multi-disciplinary care provision [13]. A study in one Belgian acute hospital, found that care pathways are an effective means of improving teamwork, increasing the organisational level of care processes and decreasing the risk of burnout for healthcare teams. Clinical pathways are also recommended as a way of building high-performance teams [14].

There is growing interest in extending care pathways to primary care and psychiatric health services. However, little evidence exists on the relationship between care pathways and service delivery coordination. Some published research addresses the effectiveness of pathways of care in psychiatry, but hardly any studies have been carried out on clinical pathways in transitioning between services. While a consensus has developed about the importance of early intervention in treatment of mentally ill patients [15], Feron [16] argues that the quoted research may be biased due to over-representations of individuals with acute mental disorders.

Katschnig [17] points out the importance of monitoring levels of healthcare delivery to ensure high quality provision. Chew-Graham [18] reported communication to be a factor which both facilitates and obstructs success depending on the quality of communication achieved. A study by Waters *et al*. [19] indicates that detailed documentation of care does not necessarily correlate highly with patients' views of treatment. Several studies show that care pathways across the primary-hospital care continuum enhance care coordination. Care coordination is also considered an important tool for implementing and evaluating care pathways in daily practice [20,21].

Providing psychiatric health services in transitions between health systems is a challenge. Patients suffering from mental illness have numerous complex needs and often require comprehensive and coherently delivered services over time.

There is no standard solution to fit everyone because every person has individual needs. However, many persons with mental health problems will have need of services from different levels at the same time. Steinacher [22] explored the change before and after implementation of clinical pathways in patients with schizophrenia. Surprisingly, these authors found that patients reported less treatment satisfaction after the implementation of care pathways compared with before implementation. They offered no explanation for this observation.

Norwegian hospitals are now focusing on the use of standardised care processes through clinical pathways and are thus responding to the political strategies of a continuous 'patient chain' and the effective use of resources. In Norway, as elsewhere, the goals and focus of the clinical pathway is to achieve optimal efficiency and improve quality of care. Changes in the organisation of clinical pathway in mental healthcare have been the focus in recent years, but the effects of the various changes need further investigation.

The overall aim of the project reported here was to evaluate the implementation of clinical pathways in mental health by:

a) Identifying the factors that obstruct in the pathway transitioning patients between district psychiatric hospital centres (DPHC) and community services and

b) Identifying the strategies that have successfully implemented clinical pathways in district psychiatric hospital centres (DPHC) and community services.

Methods

An interpretive descriptive approach was chosen [23,24] which sought to generate new insights that can help guide the applications of qualitative evidence to practice. The use of concepts was also related to the research procedure and proposed measures to achieve trustworthiness; credibility, dependability and transferability, throughout the steps of the research procedure [26-30].

All interviews were focus group interviews, characterised by the interaction between interviewees. Focus group sessions were carefully planned and discussed, taking advantage of the group dynamics to access rich information [25,26]. This study presents comprehensive summaries and abstractions of particular aspects/phenomena. Many authors, from a variety of research traditions, have addressed content analysis [26-28].

Participants

A total of 18 experienced health personnel; expert nurses in psychiatry and one psychiatrist across 2 psychiatric centres, including 2 district psychiatric hospital centres (DPHC) ambulant teams participated in 7 focus groups between 13 February 2013 and 9 October 2014.

Two decentralised specialist healthcare services and intermediate care institutions (DPHCs), shared the core purpose of responsibility for the mental healthcare of adults in a given geographical area with approximately 72,500 inhabitants, >18 years by January 2015 (Statistics Norway). The 2 DPHCs have a similar organisational structure concerning the pathological severity of the patients as well as staffing numbers. Both DPHCs offer outpatient treatment and ambulant teams as well as access to psychiatrists, psychiatric nurses, psychologists, occupational therapists and physiotherapists. Patients' diagnoses include: severe depression, severe anxiety, bipolar disorder and psychosis.

Procedure

Leaders of the DPHC and community services selected health personnel for the focus groups. Two researchers informed the selected participants and coordinated the focus groups. Two psychiatric nurses assisted in the focus group interviews, matching statements to specific informants. All provided written consent to participate in the study.

Focus groups

A semi-structured interview guide was used for the focus groups. Participants were asked to describe their views of and experiences with care pathway transitions between district psychiatric hospital centres (DPHC) and community health services. The facilitator guided the focus group discussions according to pre-prepared questions and topics to be covered, interpreted the responses, asked follow-up questions and discussed the interpretations with the participants. An assistant moderator contributed by regularly summarising and following up the key information revealed in the group discussions [29,30]. The topics on the interview guide were: planning, patient and staff cooperation, patient participation, communication, information, documentation, clinical care and treatment, medication, interdisciplinary cooperation, organisation and ethical issues. At the end of the focus group sessions we asked a general open-ended question in order to gather information that had not been covered earlier.

Two researchers facilitated the focus groups. All interviews were digitally recorded. The focus groups lasted between 1½ to 2 hours.

Data analysis

Focus group discussions were transcribed and analysed through ethnographic content analysis using template text analysis. A codebook was developed based on the variables identified by our research team at the beginning of the study as being theoretically relevant to the research questions and the literature. All transcripts were coded accordingly.

The two researchers that conducted the focus groups also performed the analysis. Both had access to all material. When disagreements arose or if there was a lack of understanding of the summaries, the full text was consulted to achieve consensus. Common meanings and a degree of agreement on the text were identified. Relationships or patterns between categories were found and enriched the material. We then looked for patterns in view of how informants showed the same relationship between the themes. Finally, the transcribed content was analysed for meaningful units about barriers and success factors. As in conventional procedures used in quality research, questions were asked until saturation of themes was reached.

Results

Three major themes emerged from the data:

1. Coordination, including documentation and communication

2. Clinical care

3. Ethics

The themes described in detail below are those that emerged in the focus groups. Selected quotations illustrate the theme under consideration. The themes and subcategories are shown in Table 1.

Theme 1: Coordination

Continuity of care

In order to provide continuity of care, DPHC nurses and psychiatrists often guide community-based nurses and general practitioners (GPs). Our informants pointed to the danger of information overload:

> "It is a balance between giving out the necessary information only and being aware of which information the receiver does not need, also patient confidentiality."

Informants agreed on the importance of communication, information and documentation in order to provide continuous care for patients. A typical remark from participants was:

> "Communication is important to give patients continuity of care."

Some informants identified a document that should be used in the patient's home in order to note the first signs of an increase in symptoms. Patients themselves can be aware of these symptoms, but the list can also function as a reminder to community nurses and patients' next of kin as to what to look out for. One of the informants described a 'crisis plan' used for psychotic patients treated in their homes:

> "The crisis plan could hang on a cupboard and give information on relevant phone numbers, warning signs of increasing mental health symptoms, also visible for next of kin."

The ambulant teams fulfil an important role for continuity of treatment initiated in DPHC and continued this in community settings. Occasionally, ambulant teams appear to exceed their briefs due to community staff shortages. Their role is to follow-up patients for short periods of time, but this sometimes extends to several years. The ambulant teams cooperate with the community ambulant team and health personnel in the community.

Table 1 Condensed meaningful units on success factors and barriers in clinical pathways

Categories	Success factors	Barriers
Coordination Continuity of care Interprofessional cooperation Resources	Right documentation to the right people in the community is important for continuity	Delays in the process of deciding level of care in the community
	Predictability and the same health personnel visiting patients give a sense of security	Unscheduled appointments between patients and health personnel
	Next of kin important to get supplementary information and cooperation. Most cooperation could be facilitated if all health personnel had direct telephone numbers to different settings, like the DPHC	Sometimes the relations between patient and next of kin can prevent an efficient pathway
		Problems connecting with the right persons to give and obtain information
	An interprofessional culture in order to provide patients with what they need	Lack of competence may generate more admissions to DPHC
	Efficient, shared, professional dialogue between DPHC and community personnel, especially during the discharge period	Lack of competence in the community may increase symptoms in the patient
	Health personnel in DPHC developing an increase in community competence	Lack of financial and human resources
	In coordination, the ability to prioritise the right structures in both DPHC and community systems	Mental health services are closed at weekends and from 16.00 to 08.00 on weekdays.
Clinical care Therapeutic communication Medication Environmental therapy Relationship	Important to enable patients to succeed in their lives	Systems that dehumanise patients oral and written
	Written plans for communication	Patients often need help to take the right (perhaps altered) medicines
	The need for one document where doctors change medication and health personnel in the ordinations (such as critical information)	Lack of up-to date medication lists from DPHC or GPs
	Facilitate activities when patients are in the community	Sometimes no direct (digital) contact between DPHS and home-based care
	Planning and meetings with other health personnel	Health personnel are told that patients do not go to activities in the community due to distances from their homes
		Lack of financial and human resources in community can lead to barriers in interprofessional cooperation
		Sometimes important health personnel are absent from meetings
Ethics User participation and empowerment Users' autonomy Ethical considerations	Patients should take part in developing their individual plans Establish a crisis plan together with the patient	If patients are not involved in creating plans for treatment it is likely that patients will not cooperate with health personnel
	Patients appear to be more empowered if plans are established after they are in their homes	Dilemma when patient and health personnel have different opinions on treatment
	Health personnel sharing a participate attitude increase the patients autonomy	
	Patients often have the best solutions for solving their own problems	
	Respectful communication to avoid humiliating the patients	

Thus, knowledge on mental status of the given patient from highly qualified ambulant team members from the DPHC is transferred to the community health personnel.

Informants described how poor communication can result in patients spending more time in DPHCs than necessary.

Written care plans were considered important for the treatment process as well as for the effectivity of the patient care. Nevertheless, the informants warned against complicated systems in creating these documents:

> "The lack of evaluation and upgrading of individual plans together with the patients seem to be a barrier in the systems."

Individual plans are often created in the DPHC and health personnel from the community should take coordinating responsibility:

> "Very few of our patients have an individual plan with the purpose to follow the patient through different health systems."

Some of our informants, experienced in psychiatric care, reported that these plans seemed to be 'put away in a drawer', rather than being employed actively in patient care.

Interprofessional cooperation

Almost all informants referred to the time-consuming activity of trying to make contact with the right person in different welfare offices:

> "It is difficult to reach the work and welfare office by phone; often we only get an answering machine. We leave a message but they never call back."

Several of the informants agreed on the fact that if the patients had problems with their finances and/or their living conditions, all attention will be focussed on these difficulties and it is therefore hard to focus on treating the mental illness itself:

> "Money and relationships trigger mental illness the most. Patients are in need of information on their rights."

Our informants pointed to the importance of the ambulant teams from DPHC:

> "It is easier to cooperate with the community when ambulant team is also involved with the patient."

> "Thus the ambulant team will work with the community mental health nurses as well as the GPs and effective solutions will be shared. The goal of good treatment is to see the patient function in their own home."

Our informants seemed to believe that different tools could be appropriate for each patient. The importance of securing interprofessional cooperation was emphasized by most of the informants:

> "Different health personnel see the patients with 'different glasses'. Thus we have a different focus on medical, therapeutic, financial, working, school, and housing issues."

The patients would not have all their needs for help covered and get an overall health service if cooperation among the staff failed:

> "If one chain is missing, it can be enough that focus will change so that the patient will lose the opportunity of having a new flat … and then I have to focus on that, because this is what the patient needs just now, and then it will affect the service as a whole."

The informants reported that special time-consuming activities were cooperation with other systems, especially the work and welfare office that are mandated to help find work for persons with mental disabilities:

> "Communication and cooperation is the half of our work. And it is very positive when the collaboration is easy and goes back and forth (both ways)."

Resources

To avoid the most serious barriers in the provision of continuous care, our informants pointed to the need for easy access to the right persons in healthcare. Not only could this reduce inpatient time, but also reduce the cost of personnel being occupied in trying to reach the right persons by telephone, instead of being involved in the treatment of patients. One of the major explanations for this lack of communication is that there is a shortage of economic resources:

> "The community teams have too little capacity. They visit the patients every 14 days and for many of the patients that is too seldom."

In almost all of the communities, mental health services are closed between the hours of 16.00 and 08.00 as well as during every weekend. Although it appears economical to close mental health outpatient services during evenings, nights and weekends, it is also possible that financial savings could be higher if the service was available on a continuous basis because patients could become self-supporting sooner, rather than being dependent on mental health services. It is easy to imagine that patients diagnosed early with schizophrenia could benefit from an open '24/7' mental health service and, as a result, be less dependent on these services in later life.

Being discharged from DPHC into the community could be delayed up to several months due to difficulties in connecting the right persons in order to set up a treatment plan prior to discharge. Our informants' solution to this problem was to establish direct mobile telephone numbers or direct mailing systems or other digital communication systems to the right person in these offices and for each patient in need of follow-up from the different professions.

Another critical point was the information flow in the discharge process from the DPHC and the admission process to the community services, especially when medication was changed. Similar digital communication systems may be the solution. In the meantime, some of the nurses described how, in addition to written documentation, they also made a telephone call to the community services to make sure that information on right medication was given. Still, the information flow on this matter is critical because of the lack of similar digital systems and it is therefore up to every individual nurse whether he/she makes the additional telephone call to pass on the information.

Theme 2: Clinical care

Therapeutic communication

Our informants emphasised the importance of being sufficiently educated and having the skills to know what is important in communication with patients in a therapeutic manner. As documented, the biggest barrier was represented by the officials in other settings, such as advisors offering advice on work opportunities, social security, housing and pensions; some of these had more focus on the limitations of the different aspects compared with the opportunities:

> "Therapeutic communication should be focused on the goals of each patient and finding the right tools to reach optimal functioning in their homes."

Medication

To provide continuous care to outpatients, up-to-date medication information is crucial to treat patients appropriately and safely. The main barrier was not between the specialist services, but in being able to pass on a current written or digital list from the DPHC to the community service, due to different digital systems. One informant said:

> "When critical information must be known in the community, written documentation is not good enough; I always make a phone call as well."

Some other critical points were identified by the informants:

> "When inscribing the patients sometimes an update medication record can be missing from the GP."

At the same time, it was pointed out that working with the information is the main task:

> "We are working with the information all the time."

The DPHC seem to have effective routines for information sharing with GPs and the psychiatric community health teams.

Environmental therapy

It is important for mental health patients to be placed in an appropriate social context with differing available activities. The local authority finances in the community tend to prioritise individual therapy and fewer social activities. Patients are often frightened to contribute in social activities, but planning activities is important. It gives the patient predictability and then some of the patients will agree to participate.

Relationship

Cooperation between patients and the requirements of different levels of healthcare is of utmost importance to maintain an acceptable quality of life for some of the patients who have to cope with serious mental disorders. Often these patients have been admitted to and discharged from hospital care on a regular basis for many years. One informant highlighted:

> "Pathways of care are like a roundabout. Some patients come home from the hospital, others *via* DPHC and back to their homes. Another re-admission to hospital and the roundabout starts again."

Relations were considered to be of utmost importance:

> "Establishing relations with the patients is very important, meeting them at the level where they are and deciding according to their own wishes … and also our professional competence … and decide together."

There has been a shift in policy in recent years from inpatient care to a focus on outpatient care, which now demands more specialised healthcare in communities. Some of our informants were very concerned about this shift because these services seemed to reduce the patients' belief in their ability to work in the future. Sometimes our informants had to spend a lot of time with the patients in order to try to re-establish their self-esteem following meetings with the work and welfare office. Perhaps easier access to the right persons could save some of the personnel costs, although other issues also arise, such as the limited opening hours of the community services in mental health. The informants emphasised the importance of cooperation between mental health community services and the ordinary medical community service as vital. The ordinary medical health services in the community are available '24/7' and patients can call them when the mental health service is not available.

Theme 3: Ethics

User participation and empowerment

The informants also point to the fact that they themselves are specialised in mental health knowledge and are also entitled to their opinions:

> "We also need to tell the patients our opinion on what is good and what is bad."

There are situations in mental health that can be chaotic and can result in violence if not dealt with:

> "User participation is difficult in situations where there is much chaos; in those situations the health personnel need to have control and put user participation on hold."

Although in situations where empowerment occurs, the main goal is that patients take part in decisions about themselves:

> "We have user participation; we try to empower the patients, but we see it from different points of view/needs. And then it is a dilemma when the patients don't do what is recommended or prescribed, for example take their antipsychotic drugs … and we continue to motivate the patients to continue the treatment."

One of the informants co-signed all relevant documents together with the patients:

> "I always engage in formulating all documents together with the patients and we sign the plans. Thus the patients also feel responsible to follow the plans, so it is also therapeutic."

User participation and empowerment are closely associated with users' autonomy.

Users' autonomy

Maintaining the patients' autonomy seemed to present a challenge in the transition into the community. It was pointed out by the respondents that it was important to build a relationship with community services before the transition from DPHC, so they could assume responsibility:

> "Here we are challenged with the patient's autonomy; because the patients have a different view of the situation. Patients often say, 'I'm not suffering from psychosis'."

Our informants emphasised that patients should take an active part in the development of care and treatment plans, together with plans for continuity of care:

> "And when we are in the patient's home, it is difficult, especially if the patient doesn't want to receive help … So the patients decide for themselves at home."

In the care pathways, dilemmas arise all the time and identifying them is of the utmost importance in maintaining the autonomy of each individual patient.

Ethical considerations

All informants regarded ethical reflections as a very important part of their work in mental health and identified ethical issues daily. The ambulant team described repeatedly trying to reach patients in their homes, by telephone or, by knocking on the door. An example of an ethical dilemma was identified in a situation where patients whose mental health symptoms might be worse did not want help to reduce the symptoms. Sometimes the offer of mental healthcare is voluntary and the only thing the ambulant team can do is be persistent in their offer to help and not give up trying to get in contact. Patients under involuntary outpatient treatment sometimes refuse to receive help from the ambulant teams in their homes and they perceive opening the door to the ambulant team as a threat. The nurses conveyed how they tried not to use threats, but rather information on what is likely to happen if they continue to refuse help. One informant put it like this:

> "We cannot always fulfil the wishes of the patient; we have laws and regulations to follow and we must therefore try to persuade patient to do things they do not really want to do."

Professional confidentiality may complicate the sharing of information that should be shared in the patient network and ethical dilemmas can arise. Sometimes, a great deal of time must be spent in trying to establish cooperation between patient and family:

> "One procedure is that the patient's relatives should be told when the patient is either admitted to or discharged from the DPHC, however patients sometimes refuse to notify their next of kin."

The critical point, according to our informants, is when agreement on discharge from the hospital unit to outpatient care in the community is made. Digital solutions have been rapidly developed, but another critical point is, of course, the privacy and ownership of medical information that should be shared:

> "Sometimes we feel like we are crossing a line, it is humiliating, we want something different than the patient and we see that the patient's behaviour may end in involuntary admission to a hospital unit. We try not to be too invasive and we try to give the patient room and time to decide."

People have the right to treat themselves badly, but it is difficult to watch. What the health personnel regard as information, patients can perceive as a threat and feel humiliated by the process.

Discussion

Communication has the greatest influence, both as a success factor and also as a barrier in the coordination process between DPHC and the community. A success factor is described by informants as efficient if they were able to reach the right persons by telephone or e-mail and get a quick response to their requests, especially before discharge. Informants considered communication to be a huge barrier when a lack of communication was present, presented as the communication/lack of communication with the offices in charge of social support, work and pension. Working with patients to motivate them to share the necessary information with community teams is of the utmost importance for continuity. Planning for future care and the use of individual plans seem to be a challenge and not all health personnel acknowledge the importance of such plans.

Informants from the community service wanted more and more rapidly available information in order to establish good continuity of care regarding medication and to establish further contact with the patient. One barrier they described was when only the GP received medication information and information on the patient. Another barrier is when the two systems lack digital solutions to communicate. The community services cannot access DPHC documentation and are dependent on other forms of information sharing. They described situations where they had not known that the patients had been discharged from the DPHC until the next meeting with the GP which could be 14 days after discharge. Correct information on medication and discharge is crucial for the continuity and appropriate care of each patient. To secure the correct information in the pathway between the DPHC and community, our nurses described how they made telephone calls to the community services to ensure that the information on medication was correct.

Informants described well educated health personnel in the community service as a success factor and the absence of knowledge in some of the community services as a barrier. The most significant barrier was reported to be a lack of communication between DPHC and community service and the Norwegian Labour and Welfare Administration. Informants pointed out that they could spend hours or even days and weeks attempting to reach the right persons before the patients could be discharged. They also identified solutions for success, such as a direct mobile telephone number, or another kind of digital communication, such as a secure chat function or a designated responsible person in each of the different offices to take responsibility when rapid responses are required. This could decrease the absolute inpatient time in the DPHC and patients would benefit from the experience of being ‘taken seriously’. Providing access to appropriate housing and also, sometimes, offers of work, could make a substantial difference to the patients’ recovery.

Sharing documents requires secure digital systems and the inter-sharing between departments in the specialist care services, including the DPHC, were reported as success factors as well as building relations with the health personnel involved in the pathways between the DPHC and the community. The lack of digital communication was a delaying factor in the coordination and information sharing between the DPHC and the community service. One of the main barriers, described both in the DPHC and community services was the lack of staff in community services, to handle both the daily mental healthcare and also the lack of support ‘24/7’.

In relation to clinical care, informants agreed that teaching patients a range of skills to increase their ability to enjoy a good life in their own home, were of utmost importance for success. They also agreed that a lack of communicating skills were present in cooperating instances, such as with the welfare and work offices.

Another success factor identified by informants was the existence of occupational therapies in the community service and the importance for patients living in their own homes to have gatherings in social settings. The community services often offer a range of social activities. The lack of these facilities often seemed to be a barrier, as patients would be isolated in their homes with no social network, having access only to the professional network mainly with the health personnel in the community. Social activities and social inclusion are recommended as important factors in recovery. The ambulant teams and the interprofessional cooperation between the different teams, especially those from the DPHC and the community service, were seen as very important factors.

User participation and autonomy appeared to represent a challenge for the health personnel visiting the patients in their homes, especially when trying to administer medication. The health personnel observe the patient in order to assess whether the prescribed medication is working or whether side effects are present or developing. The health personnel wanted to further motivate and empower the patient to continue treatment. When the staff did not succeed, they sometimes felt they had to cross a line and engage in a paternal nursing role, knowing that the patient would find this humiliating. Our informants asked themselves how much they could involve themselves when a patient has made him/herself inaccessible and their views on this situation differed with those of the patient. Maintaining an alliance and not losing contact with the patient were described as presenting ethical dilemmas if the patient and nurse have different opinions on how things should be done. The next of kin could also sometimes pose a challenge if they wanted treatment and symptoms to decrease more rapidly than was realistic for the patient. They also wanted to see more rapid results when it came to work and housing. The practice of co-signing documents together with patients seemed to be of therapeutic value, but also patients taking ownership of these to motivate them to adhere to the plans.

Conclusion and Recommendations

The main barriers to the success of the clinical pathways identified by the current research were communication errors, lack of treatment compliance due to disagreement on treatment and lack of competence in some of the elements of the treatment pathway, especially in community services due to both lack of continuity of personnel and lack of mental health nurses as well as limited working hours for ambulant teams. The main success factors were adequate direct communication systems between health personnel, patient participation in future plans and working hours of ambulant teams

Finding the right tools for information sharing should be implemented across all systems that need to share vital information and documentation in the clinical care pathways. Interprofessional cooperation and systems to communicate efficiently with the decision-makers involved in the patient’s economic, housing and work facilities was observed as crucial. It is also important to strengthen patients’ participation in decision-making in order to share ownership of the plans between patients and health personnel. Ambulant teams in community services should be available for patients ‘24/7’. The transition between health systems seem to be a critical phase in the total pathway of patient care. Therefore, there is a need for monitoring and to identify what systems can be organized in better ways to provide patients with seamless and coherent transitions.

Conflicts of Interest

The authors declare no conflicts of interest.

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RESEARCH ARTICLE

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Care pathways in the transition of patients between district psychiatric hospital centres (DPCs) and community mental health services

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Abstract

Rationale, aims, and objectives: Patients with mental health problems experience numerous transitions into and out of hospital. Primary care providers have mixed success in identifying and managing patients' needs. This study explores health personnel's experience of care pathways in patient transition between inpatient and community mental health services.

Methods: A descriptive qualitative design was chosen. Four focus group interviews with 12 informants from 7 different communities were conducted. Interviews were analyzed thematically.

Results: Two main themes were identified: integrated care and patient activation. The participants shared their experiences on topics that can affect smooth care pathways in mental health. Six promoting factors were identified for successful patient transition: opportunities for information sharing, implementation of systematic plans, use of e-messages, around-the-clock care, designating one responsible health person in each system for each patient, and the involvement of patients and their families. The following barriers were all found to impede the patients' transition between levels of care: the lack of a single responsible person at each health care level, insufficient meetings, the absence of systematic plans, difficulties in identifying the right staff at different levels, delays in information sharing, and the complexity of welfare systems negatively affecting patient dignity.

Conclusions: 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. Finally, both patient and staff in community services should be linked through a direct telephone number with around-the-clock availability.

KEYWORDS

care pathways, communication, community mental health care, district psychiatric centre, information, integrated care, patient transition, psychiatric services

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1 | INTRODUCTION

Patients with mental health problems experience numerous transitions into and out of hospital.[1] Evidence shows that patients with mental health concerns often share their problems with their primary-care provider[2,3] but that primary care providers have mixed success in identifying and managing these concerns on their own.[4,5] Because patients have a variety of preferences for care and face barriers associated with mental health treatment, this situation suggests the need for easy access to a range of treatments and providers.[6,7]

There is a growing interest in extending care pathways in primary care and 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.[8] Although there seems to be a consensus on the importance of early intervention in the treatment of mentally ill patients,[3] evidence is sparse about the relationship between care pathways and care coordination. A recent study[9] found that care pathways are effective interventions for enhancing teamwork, elevating the organizational level of care processes, and reducing the risk of burnout for health care teams in such settings. From care pathways, high-performance teams can be built.[9] Chew-Graham et al[10] pointed out that, depending on its quality, communication could function as both a promoting factor and a barrier to success. Starfield[11] identified the following key elements in the integrative functions of primary care: First Contact Care (use of services for each new problem), Continuous Care (regular source of care over time), Comprehensive Care (availability of a range of services), and Coordinated Care (linking of health care events). These 4 elements are implicitly incorporated in the health care system to improve outcomes.[12] Vickers et al[13] noted that expanding integrated mental health care in the primary care setting/services resulted in increased staff and provider satisfaction.

A study[14] evaluating the effectiveness and satisfaction outcomes of a mental health screening and referral clinical pathway for community nursing care showed that the use of a structured pathway by generalist community nurses may result in better recognition and management of problems compared with nurses' reliance on judgment alone. When studying how a care pathway model works in community mental health in the UK, Khandaker et al[15] found that it led to more focused interventions being offered. However, Steinacher et al[16] investigated the changes due to the implementation of care pathways in the treatment of patients with schizophrenia and found that the patients reported less treatment satisfaction after the implementation of pathways of care. Steinacher et al offered no explanation, and the evidence base for such pathways remains contested or in development. Katschnig,[17] for example, emphasized the importance of monitoring different levels of health care to find the best models or pathways of care. Waters et al[18] suggested that documentation does not reflect patients' views on treatment. However, several studies have revealed that care pathways improve the components of care coordination.[19,20]

A main element in the Coordination Reform in Norway,[5,21] relevant for the current study, is the commitment to ensuring that patients receive the most effective health care services possible, through cohesive and integrated care pathways, and recommends a 24-hour follow-up in the community after discharge from the hospital.

The apparent goal of care pathways is to achieve optimal efficiency and improve the quality of care as prioritized in health strategies in Norway. Thus, the current study endeavors to contribute to this area of research by exploring community health personnel's experience and providing an understanding of care pathways in the patient transition between district psychiatric centres (inpatient) and community mental health services.

2 | METHODS

To reveal important factors in care pathways for mental-health patients, we used a qualitative research design with a descriptive approach.[22]

The interviews were conducted in 4 focus groups. Prior to the focus group sessions, we discussed in great depth which questions to ask. We studied the comprehensive summaries of phenomena and events described in the focus group sessions in an effort to detect major categories, themes, and patterns, using thematic analysis.[23-25]

2.1 | Process of selection of participants

The team leaders in the community health care settings identified experienced mental health personnel. All the leaders were positive about the study and acknowledged the need for focusing on pathways of care, especially obstacles that could prevent smooth transitions. They assisted the researchers in identifying participants who would offer comprehensive and unbiased information. All our participants were involved in practical coordination in pathways of care. The inclusion criteria were > 5 years of experience in mental health care and working at least 30 hours a week.

2.2 | Participants and demographics

Twelve health employees from 7 community health care settings (1 urban and 6 rural) were interviewed in 4 focus groups. All participants were female with more than 10 years of experience in mental health. The vast majority of health personnel in mental health in Norway are women. The study included 9 nurses, 2 carers, and 1 social worker, all specialized in mental health care.

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. All phases of the study were conducted according to the Helsinki Declaration[26] and ethical principles in research. Data were transcribed and anonymized accordingly. Written consent was obtained from all participants.

2.4 | Focus group interviews

We used a semi-structured interview guide in the focus group interviews, which was developed in discussion with university and health care representatives. The participants 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 following 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 cooperation; and organization of information among health personnel. An assistant moderator contributed by regularly summarizing and following up on key information revealed in the group discussions.[27,28] 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 between 90 and 120 minutes.

2.5 | Data analysis

Interviews were transcribed and analyzed through thematic text analysis in 6 phases: familiarizing ourselves with the data, coding, searching for themes, reviewing themes, defining and naming themes, and writing up.[29] 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[30] proposed measures of trustworthiness (credibility, dependability, and transferability) were applied throughout the steps of the research procedure. The analysis of group-level data involved scrutinizing the themes, interactions, and sequences within and between groups. We performed an iterative analysis in a systematic, repetitive, and recursive process.

3 | RESULTS

Two areas of concern about care pathways between DPCs and community mental health services emerged from the analysis: (1) the need for integrated care and (2) the need for patient activation or empowerment. These 2 areas are discussed below.

No particular differences between participants from rural and urban health care were found.

3.1 | Integrated care

Integrated care occurs when health care professionals consider all health conditions at the same time, instead of adopting a fragmented, disease-specific focus. Thus, integrated treatment is more likely to be customized to individual patients, because this approach allows health care professionals to treat individual patients as a whole rather than on the basis of their separate conditions. Different dimensions play complementary roles: clinical integration, professional and organizational integration, and system integration.[12]

The community mental health teams emphasized the importance of capitalizing on opportunities for cooperation, through the establishment of routine meetings between staff in DPCs and community services to exchange information and to provide quality health care, as stated in the Norwegian government's goals for mental health care.[5]

> *"We always have the patient's consent to share information. I think that it is necessary to secure cooperation with the most important authorities, particularly in the transitional period from one organizational system to another."*

Some of the participants emphasized a positive change associated with the establishment of routine meetings at inpatient facilities. Before admission to a hospital-based service, patients were offered to be part of the planned inpatient-stay program. Participants pointed out the benefit of holding this new routine meeting.

> *"It seemed to be a very positive experience for the patient; she became more motivated to accept mental health hospitalization. Her contact specialist nurse considered the meeting as goal-oriented and emphasized that the patient had the opportunity to talk about her challenges."*

One of the participants recommended implementing knowledge-based protocols for meeting patients prior to their discharge from inpatient settings. She described the current situation as follows:

> *"Sometimes, we do not have time for a meeting prior to discharge, and we get the information by phone. There are no routines for phone calls or meetings. Different nurses choose different ways of communicating."*

The lack of standardized protocols seemed to preoccupy our participants, and they suggested several ways to facilitate the seamless exchange of important information between systems. The importance of providing and receiving correct information at the right level and time is described in a previous study,[31] which reviewed evidence on the quality of information transfer between primary care physicians and specialist mental health providers for referral and after inpatient discharge. Previous research has also revealed variability in the quality of protocols in mental health care, with differences existing between regions and among providers and, in some cases, a lack of correspondence between the provided care and the standards of evidence-based mental health care.[32]

Participants emphasized the need for new evidence-based protocols for the patient discharge process. One staff member succinctly expressed this shared sentiment when she made the following remark:

> "I think DPCs need routines for the discharge process."

Participants from community mental health services were pleased with the hospital-based meetings about the transfer of patients to community mental health services, but they noted that the information provided by the hospitals was sometimes incomplete. They felt that the delivery of complete patient information by the DPC should be a matter of standard practice when patients return home and the responsibility for their well-being shifts to the community mental health services. The historical documentation from both health personnel as well as the patient's own narratives and opinions should be clearly communicated. Knowledge about the patient was presented as more complete in the community setting compared with the knowledge that came from the DPCs. For example, 1 participant concluded:

> *"In the community, we have followed this patient over the years. We have documents and knowledge about his life and about which treatment works…"*

Importantly, our participants reported a discrepancy between the way in which DPCs and community mental health services identified the needs of each patient, separately and from the start, without cooperation.

> *Staff in inpatient services identify the need for new housing (for the patient) with health personnel present 24 hours a day. With such a high level of care, there is a risk that the patient develops a decreased level of functioning in his/her daily life.*

There also seems to be a perceived cultural and power discrepancy between DPCs and the community mental health services. Traditionally, the hospitals have had the "power" to identify the care needed by the patients when discharged. These views seem to have had an influence on the cooperation between systems, with DPCs considered as the most powerful contributors to both treatment and care of the patients.

> *"We should instead work "shoulder to shoulder". Now, it is more like the different systems work for themselves."*

Sometimes, patients refuse to engage in the sharing of information. In such cases, community care services struggle to identify the right level of care required.

> *"In those cases, patients will not establish a relationship with us [community staff] and will not experience our professionalism."*

During the focus group sessions, we found that inpatient staff send information by letter to the community mental health services, a choice of communication method that causes delays in establishing health care in the communities. One participant explained the potential effect of these delays, as follows:

> *"We could potentially provide health care too late, not knowing that the patient was in need of our services."*

A new e-message system[33] seems to have changed the routines for communication between DPCs and community mental health services. As 1 participant puts it:

> *"It is easier to get documented information when we ask for complementary health information by e-messages … then, they are obliged to respond."*

Although the e-message system was introduced to support patient transitions across the healthcare sector, the participants experienced a lack of information and cooperation and stated that, sometimes, they did not get the messages at all.

> *"What I find scary about e-messages is that it is like an ordering service, without cooperation. We have to get ready for the service they ordered… but we have waiting lists and a tough prioritization process when deciding who we can help…"*

A previous study[34] identified a lack of communication between DPCs and community mental health services, and the Norwegian Labor and Welfare Administration (NAV) as a significant barrier. The participants in that study pointed out that they could spend hours, days, or even weeks attempting to reach the right person with the authority to make decisions regarding the discharge of patients.

> *"And we are critical of NAV all the time. We send requests for economic help and support, money for medication, applications for jobs for the patients, or other welfare or coverage of expenses."*

For some patients, attending meetings and gleaning information from these meetings could also be challenging.

> *"It is as one of the patients always says: There is a big difference depending on the level of sickness. If my anxiety level is high, I remember nothing of what happened there."*

All participants agreed that part of their role is to secure the information given in meetings and inform the patients afterwards, to ensure that they fully understand the decisions made.

Another topic identified in the interviews was the lack of resources needed to give quality mental health care to patients. The participants complained about not having the time and resources at work to prevent the development of mental health problems in their communities.

> *"Earlier, we had a mental health nurse working on preventing the development of mental illness among children and young people at school. This service is now reduced from three days a week to one day a week."*

In addition, the interviews revealed the negative impact that economic problems in communities had on the training of mental health nurses. One participant expressed her concern with the following remark:

> "The training of the mental health staff is reduced, and that is alarming."

The reduced training was deemed to have come about as a cost-saving initiative, and participants were anxious to hold on to current resources in the face of this and determined to fulfill their duties of care in mental health work, regardless of this context.

3.2 | Patient activation

Patient activation is considered an important and empowering element in health care reforms. It involves giving patients information that they can understand and act on, and providing them with support that is customized to their needs, so that they are equipped to learn how to manage their own health. Activated patients develop their own understanding of and are engaged in their role in healthcare processes.[35,36]

As evidenced by the interviewees' responses, the community mental health teams emphasized the importance of patient involvement and participation in mental health care. One participant offered the following insight:

> *"We are making a decision contract together with the patient—what their opinions and goals are—and we have an ongoing dialogue with him/her, to make sure that it is what the patient wants to achieve."*

The very experienced personnel interviewed for this study emphasized that the transition from inpatient status to living in the community could be seen as a challenge for patients.

> *"The transition to going back into the community with only a few visits every week, is quite overwhelming when you have been together with others 24 hours a day or you could get help 24 hours a day."*

This transition involves patients being discharged from a hospital unit and returning to their homes with less chance to talk to someone around the clock. Unlike the general population, most patients with mental illness live alone, and for some, their social network revolves around those they encounter as part of receiving their health care.[37]

It is not easy for patients to make the transition from living in a safe environment where someone is always available to provide advice, to living at home, where they must try to figure out everything, mostly on their own. Another problem that may arise during the transition phase is that some patients might feel healthy when discharged from hospital-based services and, therefore, refuse to receive follow-up care from the community mental health nurses. On some occasions, this could lead to a relapse.

> *"Some patients think they are healthy and that every problem is solved when they leave the inpatient services; therefore, they don't want follow-up from any professional personnel… Then, they often have a relapse weeks or months later."*

In the community, the mental health teams work together with the ambulant teams to provide follow-up care to the patients discharged from the inpatient setting in order to maintain continuity in the provision of mental health care. One participant underscored the importance of providing follow-up care and of cultivating cooperation between the health care personnel involved:

> *"When the patients are discharged [from DPC], we think that it is very important [to continue] with visits and treatment from the ambulant team, preferably together with a community mental health nurse."*

Our participants found that coordinated visits to newly discharged patients in the community that involve *both* inpatient and community staff are useful, especially when the patient is new to receiving community mental health services. The staff from the hospital-based service can introduce the community mental health nurse(s) to the patient, and all 3 parties can discuss the proper treatment and follow-up.

In addition, the interviews conducted for this study revealed that mental health team members focus not only on the patients but also on their families and settings.

> *"We support and empower them to improve the patient's function, but in the community, we not only have the patient, we very often also have the whole family, in many different settings."*

During the interviews, the members of the community mental health teams emphasized how challenging it is for patients to cooperate with NAV.

> *"Many of the patients with whom I have a therapeutic dialogue emphasize that it is a challenge to cooperate with NAV. They don't feel that they are being seen or respected."*
>
> *"They are frightened about not fulfilling what is expected from them. Some seem to be afraid that, if they don't say yes to everything, they might lose money or benefits from NAV."*

In addition, NAV's housing policy affects patients' sense of dignity. To have proper housing seems to be an important factor in patients' lives, as evidenced by 1 participant's comment:

> *"If patients get respectable housing, we see that they begin to flourish and get a new outlook, both on themselves and on their way of life."*

Healthy Life Centres have recently been established as a public health care service in Norwegian communities. They emphasize physical activity and offer counselling, support, and education on issues related to mental health. One participant noted the connection between physical health and mental health:

> *"Many of the patients struggle with obesity. It is a part of their mental problem. It can also be a side effect of medication. It can be associated with too little activity. We offer a course on diets with a focus on learning how to shop for food and how to make simple, healthy food."*

However, some patients with mental health problems who attend the diet course feel stigmatized because they sense that others attending this open course are watching them with suspicion.

> *"All kinds of people are participating there, and some of them look down on people suffering with mental problems. Regardless, some patients have attended the course."*

The interviewees also discussed the level of responsibility for training patients with mental health problems in the communities. One participant described how opinions differed regarding this issue:

> *"We tried to cooperate with the inpatient services to offer a course in coping with depression. We felt that the DPCs were also responsible for training the patients, but the DPCs felt that the communities had to arrange the courses themselves."*

The community mental health nurses seemed to be aware of their role in sharing responsibility for the future training of patients, but they also noted that they lacked the resources to fulfil this role.

> *"… but we need more professionals, competence, and resources."*

A recent study[38] showed that the use of peers as co-educators might contribute to the implementation of a different mental health care delivery system, a system that ensures patient activation and participation in the treatment.

Our participants found it important to have an action plan in place for those patients whose health worsens after discharge from the DPCs. One participant explained the importance of having such a plan, as follows:

> *"It is necessary to have a plan for readmission to the inpatient services if we observe that patients are not confident and are in need of more security, so they have an opportunity to go back and forth."*

Another participant acknowledged the difficulty encountered by some patients following their discharge:

> *"Moving back to a house or flat can be quite challenging. Not all patients are capable of coping straight away."*

Our participants were familiar with the allotment of low-threshold beds (self-referral admissions) in hospital-based services/DPCs. This was considered an opportunity for patients to be more involved in their own care.

In relation to clinical care, the participants agreed that teaching patients a range of skills to increase their ability to have a good life in their own home was of utmost importance for success.

We have summed up our findings in Table 1.

4 | DISCUSSION

The main promoting factors affecting smooth care pathways in mental health found in this study were that there should be opportunities for information sharing between inpatient and community mental health services, the identification of health personnel responsible for carrying out the tasks of information sharing and implementation of systematic procedures, the use of digital messages, around-the-clock care, and patient involvement. Barriers that prevent the actions described earlier are lack of a responsible person in each level of care; insufficient meetings, protocols and systematic plans; delays in information sharing; and welfare systems negatively impacting on patient dignity.

The mapping of responsible personnel will secure smooth pathways in the transition from being an inpatient to being a user of community mental health care. Our participants also shared their opinions on other important aspects of integrated care.

Patients face challenges in finding their way through the different systems. Patients are in need of support around the clock in order to be activated and empowered to be part of the decision-making process and develop coping skills.

The gaps between inpatient care and community care appeared when the different services wanted others to be responsible for activities, visits, admission, or new admission to other levels in health care. These gaps were quite evident when participants described differences in opinion between DPCs and community mental health services regarding their respective responsibilities for courses offered to patients with mental health problems. The roles of inpatient and community staff should be clearly delineated so that the different health care services own their respective responsibilities. Participants concluded that improved communication strategies seemed to be the best way of achieving this.

Information seems to be the key to a smooth transition of patients with mental health conditions from inpatient to community facilities. The community mental health team members emphasized the importance of different opportunities to exchange information and their responsibility in providing quality health care, as stated in the Norwegian government's goals for mental health care. If the DPCs confirm that a patient has little need for follow-up care because of excellent self-care, there is no need for additional information. However, if the patient has required 24-hour-a-day care and experienced

TABLE 1 A summary of participant views in the transition process between district psychiatric hospital centres (DPCs) and community mental health services

Main Themes/Categories	Promote Patients Transition	Impede Patient Transition
Integrated care		
Information	Opportunity for information sharing	The lack of a single responsible person at each level. Delays in information sharing.
Documentation	Implementation of systematic plans. Use of e-messages.	The lack of systematic plans.
Team work/ambulant	Around-the-clock care. One responsible health person in each system for each patient.	The lack of meetings. Difficulties in identifying the right staff at different care levels.
Resources	Gearing up community services to specialized care.	Lack of specialized personnel.
Patient activation		
User involvement and autonomy	Involvement of patients and their families in the admission and treatment process.	
Mutual learning and training	Day centres and healthy life centres that offer counselling, support on issues related to mental health.	Lack of day centres and personnel for training and support.
Relationship		The complexity of welfare systems negatively affected patient dignity.

multiple readmissions during the past year, the community personnel need a detailed care plan to avoid serial readmission to hospital-based care. In particular, our participants pointed out the urgent need for an action plan when patients begin to relapse in the community. Importantly, health personnel involved in deciding the level of care for each patient must take into consideration the comprehensiveness of the written and oral information about their health alongside the social context, resources over time, ongoing psychological symptoms, and the daily functioning of the patient.

The new e-message system appears to have changed the routine for communication across DPCs and community services, providing more complementary health information. However, these are also subject to a lack of cooperation and failure to receive messages. That said, experiences from a recent study in Norway[33] showed that electronic messaging is more efficient and less time-consuming than previous means of communication and is considered to be a useful tool for communication and collaboration in patient transitions.

Patients sometimes refused to share information about their health and, consequently, community services had difficulties in choosing the right level of care. With systematic written procedures and documentation, it would be much easier for community personnel to find out what has or has not been done, and the randomness in the process of being transferred as a patient from 1 system to another, would decrease. This is in line with Durbin et al,[31] who suggested that the use of structured forms to share information could have a positive effect on the necessary flow of information and possibly reduce the time spent on finding the right people in the various systems.

The pathways of care seem to be a bureaucratic process, resulting in difficulties for patients wanting to complain if they find their legal rights to be compromised. Although the decisions are made on the basis of the knowledge of each discipline and on the economic resources available to provide equal treatment for patients, the knowledge of the different disciplines should be accorded greater weight than the economic resources available in decisions related to care.

The shift in specialized care from hospitals to communities is part of a trend to promote discharge from hospitals at the earliest possible stage. For this to succeed, there is a need for sufficient staffing levels of specialized health personnel—in inpatient services—focused more on treatment, and community contexts, focused more on care. A study in Norway[39] on care pathways in mental health care highlighted the important contextual knowledge of each kind of health service. However, care pathways could become regulation tools that limit professional autonomy and devalue contextualized knowledge.

The participants also described increased patient satisfaction and motivation to receive care when they are more fully involved in the admission and treatment process. This finding is in line with Tveiten et al,[40] who advised giving patients a voice to express their concerns and have these addressed. In addition, a recent study in the UK[1] showed a loss of the patient's voice at the key transition points into and out of acute inpatient mental health care. Moreover, as reported earlier,[34] the establishment of relationships among the 3 parties involved (patients, inpatient staff, community staff) was considered to be of utmost importance in the transition process between inpatient and community mental health care.

Participants reported that health personnel tried to involve patients to a greater degree in the decisions concerning their health care and future plans. However, a shared decision-making process can be a difficult experience for some patients, especially those who have cognitive difficulties because of their illness. Health care professionals need to identify to what degree patients want to be part of the decision-making process, but, as a main rule, a shared approach to this should be promoted as first choice, when appropriate.[41,42]

Research has provided evidence of the benefits of greater patient involvement.[43] A recent study[44] 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. However, a discourse analysis of the concept of patient involvement in mental health nursing in the UK[45] pointed out the implications for the role of mental health nurses and concluded that nurses may need to relinquish power to patients if true involvement is to occur.

Some of the communication strategies to meet the needs of patients should focus on a better sharing of knowledge through enhanced teamwork and interprofessional collaboration. Annells et al[46] found that the sharing of knowledge ensured an effective referral process. This finding was also described by Beach and Oates,[47] who found that a key aspect of the work of mental health nurses is sharing information about individuals through records. They concluded that shared information through electronic records reduces unnecessary documentation and increases collaboration and the quality of direct care. Our participants described general practitioners as the most important collaborating partners for community mental health nurses. In addition, our participants called for improved therapeutic communication skills among providers of somatic home care, as well as closer cooperation with somatic home-care services.

The participants also emphasized that it is no longer easy for chronically ill patients to be granted admission to inpatient facilities due to the policy that most of the treatment should be in the patients home instead of in hospital. So there seems to be a discrepancy between the policy and the needs in the communities. It would be interesting to explore the patients views on this matter. Communities with economic problems are struggling to provide the resources and further training necessary to ensure that patients receive quality mental health care. Finally, there should be less emphasis on developing and enforcing bureaucratic rules and regulations for health care, and more emphasis on producing competent professional health personnel and on providing help to patients around the clock. This shift in emphasis is an approach that could be less costly when measured over time. More research should also be conducted on the effectiveness and efficiency of the planning of care pathways from a longer-term perspective than that of the current hospital/community admission process. Patients will probably be more compliant with treatment if they participate in the decision-making process, in accordance with their rights.

4.1 | Limitations and strengths of the study

The findings of our qualitative 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 key personnel about promoting factors and 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. 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 countries. Our findings indicate that further and more comparative research could test and build upon these initial findings.

5 | CONCLUSION AND RECOMMENDATIONS

The mapping of responsible personnel will secure the follow-up of the key findings in the point of transition between services, in terms of cooperation, information, and documentation.

To ease the transition for patients leaving around-the-clock treatment and care and reentering the community, it is important to secure proper follow-up at the right time. If communication fails, people in need of re-admission might not be identified.

A setting with a single responsible person (and system) and clarified procedures should be implemented at each stage in care pathways to avoid waivers of liability and to provide transparent systems that can be easily monitored by health personnel and patients. Such a person could be responsible for coordinating services as well as liaise between social- and health systems and patients.

Both digital and telephonic sharing of information and communication should be implemented and in place before admission to a hospital-based service, and before and after discharge back to the community. In order to secure effective information sharing, all parties should have the phone number of a named, responsible coordinator in each health care and social care system to allow easy access to all parties. Regular meetings should be scheduled, in which mental health personnel can share and discuss key information with the social care system, to avoid the long current delays that extend inpatient status and block satisfactory transition to the community setting.

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CONFLICT OF INTEREST

None declared.

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ORIGINAL PAPER

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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."[1] Importantly, these patients have diverse preferences for care and face a variety of barriers associated with mental health treatment. This context suggests the urgent need for easy access to a range of treatments and providers.[2] The Joint Commission Center for Transforming Health Care (USA) defined transition as the process or period of

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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.[3] 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.[4,5]

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.[6]

A recent study in the United Kingdom[7] 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[7] 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[8] 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.[9-11] 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.[12] 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.[13]

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.[14] Moreover, as reported earlier,[15] 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.[16]

What is clear is that shared decision making is not a simple or straightforward matter. As Stiggelbout et al[17] 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.[18,19] 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,[20,21] 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.[22] 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[23,24] 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.[25-27] Three focus group interviews were conducted with a total of 10 informants, three men and seven woman 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.[28,29] 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 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.[30]

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[31] 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.[32,33] 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.[33-35]

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.[36]

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.[28,29] 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[37] 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,[38] 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):

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.

3.1 | 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.

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[39] 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.[5,40]

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[41] who identified how, in phases of poor mental health, patient participation demands sensivity 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,[42] 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[43] 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.[44] Shared decision making is more than just efforts to impart knowledge to informants. It also involves engagement and eliciting and integrating decisions.[45]

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,[14,15] 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.[21] 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.[46,47] 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[48] 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.[49,50] 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.[41]

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. [51] 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.[52,53]

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.[54-56] 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.[54-56]

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.[39,42,57] 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,[38] 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[58] 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[59] 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[60] 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[61] 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[62] 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.[63] 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.[14]

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,[15] 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.

AUTHOR CONTRIBUTIONS

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APPENDICES

Interview guide health personnel

Interview guide former patients

Information sheet with declaration of consent

The Regional Committees for Medical and Health Research Ethics (REC)

(Presentation assessment)

Editing Certificate

Prosjekt: Pasientforløp i overgangen mellom spesialisthelsetjenesten/DPS og kommuner - Samarbeidsprosjekt mellom DPS/Kommune/Høgskole 2014-2016

Intervjuguide – Psykiske helseteam og Ambulante team

- **Litt om bakgrunn for deltakere og presentasjon av teamene.**

Hvilke erfaringer har du gjort deg om helhetlige pasientforløp når det gjelder:

- **Planlegging/Samhandling/Kommunikasjon/Informasjon**

Hvilke kritiske punkt har du observert hos pasientene når pasient/bruker passerer de ulike tjenestenivåene i overgangen mellom Spesialisthelsetjenesten/DPS og kommune(hjem)?

Hvilke utfordringer har du opplevd når det gjelder pasientens inn- og utskriving.

På hvilke måter videreføres informasjon til/fra kommunehelsetjenesten og spesialisthelsetjenesten?

- **Dokumentasjon**

Hvilken betydning har individuell plan, pleieplan og behandlingsplan i forhold til å kvalitetssikre og skape kontinuitet i det tverrfaglige tilbudet hos pasienten?

Hvilke erfaringer og observasjoner har du gjort deg ved bruken av sykepleiesammenfatning, epikriser og informasjon i overgangen mellom DPS og kommune?

Hvordan opplever du at dokumentasjonen av tjenestene sikrer kvalitet og kontinuitet og styrker det tverrfaglige tilbudet til pasient/bruker i overgangen til kommune?

- **Brukermedvirkning/Empowerment/Etiske forhold**

Hvordan opplever du at pasient/bruker medvirker til planlegging og gjennomføring av tjenestetilbudet?

Hvordan ivaretas pasientens/brukers selvbestemmelse/autonomi og integritet/ukrenkelighet i overgangen?

Hva har du lært av dette i samhandlingen med pasienter/brukere og evt. pårørende?

- **Behandling**

Hvilke forhold synes å være viktigst for pasienten, og eventuelt pårørende, i møte med helsepersonell og instanser når det gjelder behandlingen(medisinering/miljøterapi/møter/koordinering)?

- **Tverrfaglig samarbeid**

Hvordan opplever du at samarbeidet mellom de ulike tjenestene sikrer kvalitet og kontinuitet?
Hvilke forhold styrker det tverrfaglige tilbudet til pasient/bruker i overgangen til kommune?

- **Hinder og suksessfaktorer**

Hvilke hinder og suksessfaktorer i helhetlige pasientforløp ser du i samarbeidsprosessen mellom psykiske helseteam og ambulante behandlingsteam?

Hvordan tenker du at et godt *helhetlig pasientforløp* mellom kommunehelsetjenesten og spesialisthelsetjenesten bør være i fremtiden, og hva er de viktigste faktorene i dette forløpet?

- **Andre kommentarer?**

Prosjekt: Pasientforløp i overgangen mellom spesialisthelsetjenesten/DPS og kommuner - Samarbeidsprosjekt mellom DPS/Kommune/NTNU 2015-2017

Intervjuguide – pasienterfaringer

Hvilke erfaringer har du gjort deg om helhetlige pasientforløp når det gjelder:

- **Planlegging/Samhandling/Kommunikasjon/Informasjon**

Hvilke kritiske punkt har dere observert når du som pasient/bruker passerer de ulike tjenestenivåene i overgangen mellom Spesialisthelsetjenesten/DPS og kommune(hjem)?

Hvilke utfordringer har dere opplevd når det gjelder inn- og utskriving.

På hvilke måter videreføres informasjon til/fra kommunehelsetjenesten og spesialisthelsetjenesten?

- **Dokumentasjon**

Hvilken betydning har individuell plan, pleieplan og behandlingsplan i forhold til å kvalitetssikre og skape kontinuitet i det tverrfaglige tilbudet (for dere som pasient/bruker)?

Hvilke erfaringer og observasjoner har du gjort dere ved bruken av sykepleiesammenfatning, epikriser og informasjon (klinisk og digital) i overgangen mellom DPS og kommune?

Hvordan opplever dere at dokumentasjonen av tjenestene sikrer kvalitet og kontinuitet og styrker det tverrfaglige tilbudet til pasient/bruker i overgangen til kommune?

- **Brukermedvirkning/Empowerment/Etiske forhold**

Hvordan opplever dere at dere som pasient/bruker medvirker til planlegging og gjennomføring av tjenestetilbudet?

Hvordan ivaretas deres (pasienten/bruker) selvbestemmelse/autonomi og integritet/ukrenkelighet i overgangen?

Hva har du/dere som tidligere pasienter/brukere og evt. pårørende lært av dette i samhandlingen med helsepersonell i overgangen?

- **Behandling**

Hvilke forhold synes å være viktigst for pasient/brukere, og eventuelt pårørende, i møte med helsepersonell og instanser når det gjelder behandlingen (medisinering/miljøterapi/møter/koordinering)?

- **Tverrfaglig samarbeid**

Hvordan opplever du/dere at samarbeidet mellom de ulike tjenestene sikrer kvalitet og kontinuitet?
Hvilke forhold styrker det tverrfaglige tilbudet til pasient/brukere i overgangen til kommune?

- **Hinder og suksessfaktorer**

Hvilke hinder og suksessfaktorer i helhetlige pasientforløp ser du/dere i samarbeidsprosessen mellom psykiske helseteam og ambulante behandlingsteam?

Hvordan tenker dere at et godt *helhetlig pasientforløp* mellom kommunehelsetjenesten og spesialisthelsetjenesten bør være i fremtiden, og hva er de viktigste faktorene i dette forløpet?

- **Andre kommentarer?**

NTNU

HELSE MØRE OG ROMSDAL

Forespørsel om å delta i forskningsprosjektet ’ Pasientforløp i overgangen mellom spesialisthelsetjenesten/DPS og kommuner’

Vi er en prosjektgruppe med fagpersoner fra NTNU, som gjennomfører et forskningsprosjekt om ambulant arbeidsmåte og pasientforløp i overgangen mellom DPS og kommuner. Psykisk helsevern har mange pasienter/brukere med sammensatte behov, og er en stor og viktig målgruppe som trenger helhetlige og sammenhengende tjenester over tid. Erfaringer fra denne studien vil derfor gi ny kunnskap som kan overføres til andre DPS’er og helsetjenesten i kommuner.

Pasienters deltagelse er særlig anbefalt i ‘Samhandlingsreformen’ i det den fokuserer på pasientforløp og økt medbestemmelse. Involveringen fra pasienter og deres organisasjoner skal påvirke til hvordan disse forløpene blir gjennomførte på en bedre og systematisk måte. Ved å analysere og beskrive gode pasientforløp, kan en fremme tiltak for økt samhandling av tjenestene. Det er behov for undersøkelser, slik dette prosjektet også har hovedfokus på.

Det vil bli brukt en kvalitativ forskningsmetode, fokusgruppe intervju brukes som instrument. Deltagelse i prosjektet innebærer at du vil delta i et fokusgruppeintervju (6 – 8 personer) i løper av uke 6 (7.-10.februar) 2017. Hvert av intervjuene vil ta om lag en time. Særlig fokus vil være tiltak, deling av informasjon, kommunikasjon, dokumentasjon og hvordan samhandling foregår mellom de ulike grupper mellom DPS og kommune.

Det er helt frivillig å delta i prosjektet og du kan på hvilket som helst tidspunkt trekke deg, uten å måtte begrunne dette nærmere. Du vil da få slettet de opplysninger som er registrert om deg og innsamlede data om deg vil bli anonymisert. Opplysningene i prosjektet behandles konfidensielt. Opplysningene oppbevares og bearbeides avidentifisert, dvs. at ditt navn er erstattet med et referansenummer. Det er ingen andre enn prosjektgruppen som vil få tilgang til de personidentifiserbare opplysningene. De er underlagt taushetsplikt og opplysningene vil bli behandlet strengt konfidensielt.

Resultatet av studien vil bli publisert uten at den enkelte kan gjenkjennes. Etter at prosjektet er avsluttet 31.12.2017, vil opplysningene bli anonymisert, opptak og navnelister slettes. Dersom det skulle bli aktuelt å gjennomføre en oppfølgingsundersøkelse, vil du i så fall motta ny informasjon og ny forespørsel om å delta. Prosjektet er tilrådd av Personvernombudet for forskning, NSD - norsk senter for forskningsdata AS.

Med vennlig hilsen

Eva Walderhaug Sæther   Marit Følsvik Svindseth   Valentina Cabral Iversen

Pasientforløp i overgangen mellom distriktspsykiatriske sentra og kommunehelsetjeneste – Samarbeidsprosjekt mellom DPS/Kommune/NTNU 2015-2017.

Samtykkeerklæring fra pasient/helsepersonell ved innsamling og bruk av personopplysninger til forskningsformål

Dersom du ønsker å delta i undersøkelsen, er det fint om du signerer den vedlagte samtykkeerklæringen og returnerer den i den frankerte konvolutten i løpet av to dager.
Har du spørsmål om i forbindelse med denne henvendelsen, eller ønsker å bli informert om resultatene fra undersøkelsen når den foreligger, kan du gjerne ta kontakt med meg som prosjektleder, på adressen under.

Eva Walderhaug Sæther
evawalde@ntnu.no
Mobil:92285927

Sendes: Eva Walderhaug Sæther, NTNU Ålesund, Institutt for helsevitenskap, 6025 Ålesund

--- Klipp

Jeg har lest informasjonsskrivet og samtykker i å delta i dette prosjektet og at opplysninger innhentet direkte fra meg kan benyttes.

Erklæringen er basert på fri vilje og gjensidig tillit mellom meg og prosjektleder/prosjektgruppe.

……………………………………………………………………………………………………..

Sted **Dato** **Underskrift**

REK
REGIONALE KOMITEER FOR MEDISINSK OG HELSEFAGLIG FORSKNINGSETIKK

Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK midt	Marit Hovdal Moan	73597504	18.06.2018	2018/1181/REK midt
			Deres dato:	Deres referanse:
			12.06.2018	

Vår referanse må oppgis ved alle henvendelser

Eva Walderhaug Sæther
NTNU

2018/1181 Pasientforløp i overgangen mellom DPS og kommune

Vi viser til innsendt fremleggingsvurderingsskjema datert 12.06.2018. Henvendelsen har blitt vurdert av komiteens sekretariat.

Komiteens prosjektomtale
Komiteen oppfatter prosjektet som en studie designet for å undersøke hvordan overgangen mellom ulike organisatoriske systemer i helsetjenesten kan gjøres så smidig som mulig for personer med psykiske lidelser. Forskningsspørsmålene er:1. Hvilke hindringer og suksessfaktorer møter helsepersonell og (tidligere) pasienter i overgangen mellom DPS og kommunehelsetjenesten. 2.Hvilke faktorer kan forbedre kvaliteten i pasientforløpet i overgangen mellom tjenestene. Data innhentes gjennom semistrukturerte intervju. Studien er samtykkebasert, og er allerede gjennomført.

Vurdering
Komiteen mener at prosjektet ikke framstår som medisinsk og helsefaglig forskning; det vil si, forskning som har til hensikt å skaffe til veie ny kunnskap om sykdom og helse. Prosjektet er iht. helseforskningslovens § 2 og § 4 derfor ikke framleggingspliktig, og kan gjennomføres og publiseres uten godkjenning fra REK. Vi minner imidlertid om at dersom det skal registreres personopplysninger, må prosjektet meldes til Norsk senter for forskningsdata (NSD).

Merknad

1. Vurderingen er gjort med bakgrunn i de innsendte dokumenter og er kun å betrakte som veiledende, jf. forvaltningsloven § 11. Dersom du ønsker at det skal fattes et formelt enkeltvedtak etter forvaltningsloven, må du sende inn en full prosjektsøknad til REK. En prosjektsøknad blir komitébehandlet iht. oppsatte frister.
2. Komiteen minner om at medisinsk og helsefaglig forskning må være forhåndsgodkjent av REK før igangsettelse.

Med vennlig hilsen

Hilde Eikemo
sekretariatsleder, REK Midt

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Challenges and barriers in clinical care pathways: Patients and healthcare professionals experiences in the transitional process between primary to secondary mental health services

prepared by the authors

Eva Walderhaug Sather

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