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Palliative psychiatry

PERSPECTIVES

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Additional curative approaches may do more harm than good in patients with severe mental illness who continue to experience symptoms despite multiple attempts at treatment. This highlights the need for palliative psychiatry.

Illustration: Espen Friberg

Many psychiatrists are well aware that some patients with severe mental illness never recover, even after many years of extensive treatment. These patients often experience persistent symptoms, low levels of functioning and repeated contact with healthcare services without significant improvement. Despite representing a relatively small proportion of patients in mental health care, these patients use a considerable share of healthcare resources – often without any obvious benefit to their health or quality of life.

However, it is not primarily resource use that motivates us to write about palliative psychiatry. Many people have expressed to us serious concern about whether the most severely ill psychiatric patients are receiving the right care. Several believe that these patients are either discharged with minimal follow-up and forgotten or are subjected to unduly aggressive interventions. Palliative psychiatry has been proposed internationally as an approach for such patients, but what does palliative care in psychiatry actually entail? Who might benefit, and is the field of psychiatry in Norway prepared for it?

What is palliative psychiatry?

Palliative psychiatry is not about giving up on the patient, but about shifting the focus from a curative approach to helping them live a good life despite mental health challenges (1). Palliative care therefore involves a fundamental change in goals – from reducing psychiatric symptoms to alleviating physical, psychological and existential suffering (2). When hope for recovery fades, existential questions about meaning, identity and the future often take centre stage. This focus on existential concerns may constitute the main distinction between curative and palliative approaches (3).

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The rationale behind curative treatment in psychiatry is that alleviating psychiatric symptoms will *indirectly* lead to improved functioning and quality of life. While generally appropriate in the early stages of mental illness, this approach becomes problematic for those who do not recover despite repeated attempts at treatment. In such cases, a palliative shift in strategy is warranted, in which the sequence is reversed: there is acceptance of the psychiatric symptoms, and the focus is placed *directly* on quality of life. Any resulting improvement in functioning or reduction in symptoms is considered a bonus.

Professionals in the field of substance use have embraced a palliative perspective through opioid substitution therapy (OST). This approach has generated controversy because some view it as 'giving up on' the patients. Whether OST is curative or palliative, however, depends on the treatment goal. OST is often curative, particularly for young adults who need stability in their lives. In such cases, the goal is long-term tapering, typically using medications with limited psychotropic effects (such as Subutex). For other patients, particularly those with long-term, treatment-resistant opioid dependence, such treatment may be more palliative (such as heroin-assisted treatment). In these cases, the goal is no longer recovery, but rather the alleviation of suffering, stabilisation of the psychosocial situation and reduction of destructive behaviours. This demonstrates that a palliative mindset already has a foothold in certain areas of psychiatry, even if it has not been explicitly labelled as 'palliative care'.

Many interventions thus take on new significance and purpose when the overarching goal of treatment changes. Psychotherapy becomes focused on providing existential care rather than achieving change, and the primary aim of medication shifts from cure to improving quality of life. Adopting a palliative approach could also help reduce the use of intrusive interventions, such as forced feeding, involuntary hospitalisation and involuntary medication, if there is recognition that these measures do more harm than good.

Clinical practice

Clinical examples can help illustrate palliative psychiatry in practice. In cases of severe and long-term anorexia, a pattern of partial remissions, repeated hospitalisation and treatment refusal is often observed. The requirement to gain weight could be perceived as threatening, prompting the patient to withdraw, which in turn can result in a dangerously low body weight. In such cases, a palliative approach involves shifting the focus from weight to quality of life, prioritising harm reduction, somatic monitoring, relational support and social stability over weight gain. In extreme cases, this may involve respecting the patient's wish to die (4).

Medication-resistant schizophrenia carries a significant risk of iatrogenic harm, which is negative consequences directly caused by treatment. This type of harm can be either physical, such as adverse effects from polypharmacy and high doses, or psychosocial, such as treatment fatigue, learned helplessness and loss of trust in the health service after repeated unsuccessful attempts at treatment. A palliative approach in such cases could involve dose reduction and minimisation of side effects rather than maximising efficacy, a higher threshold for hospitalisation during deterioration, and interventions that improve perceived quality of life. Palliative care for psychosis does *not* involve phasing out necessary antipsychotic medication and allowing the patient to deteriorate; the focus instead is on avoiding prolonged hospital stays and respecting the patient's life goals, even when these do not align with societal norms.

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Patients with long-term suicidality and self-harm often face a system that alternates between rejection and overprotection. Some of these patients have undergone multiple rounds of evidence-based, symptom-focused treatment but continue to suffer. In such cases, a palliative approach can involve relational support rather than change-oriented therapy, acceptance that self-destructive behaviour may be a self-chosen coping strategy, or pharmacological interventions to relieve intense inner pain when other treatments have failed to do so. The goal is no longer to eliminate the disorder, but to alleviate suffering. In palliative care, the patient will, of course, not receive the same intensive follow-up as in a curative pathway but will receive sufficient existential support and palliative care to cope with life. Offering patients a respite from the pressure of treatment not only strengthens their sense of responsibility, it also helps reduce the power imbalance between the patient, who struggles to change, and the system, which requires change in order to continue offering help.

Extremely violent patients with substance use disorders, dissocial personality disorder and psychosis can live for many years in secure units with no realistic prospect of safe reintegration into the community. In such cases, the aim of curative treatment is to release patients, which entails considerable risk of harm to innocent people. A palliative approach may instead involve acknowledging the limited rehabilitation potential of some of these patients. The primary goal is no longer full reintegration into the community, but a stable life in a safe, sheltered and substance-free environment. In such cases, a palliative approach may entail more, rather than less, use of coercion.

When should palliative care be considered?

Fortunately, there are many effective treatments in psychiatry, and a large proportion of patients recover. Palliative psychiatry is therefore only relevant for patients with severe and persistent mental illness, where the potential for harm from further attempts at curative treatment outweighs the expected benefit, i.e. where the 'point of futility' has been reached. A palliative approach thus necessitates a more systematic assessment of when this point occurs and how futility in psychiatry should be defined (5).

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In somatic medicine, the point of futility is often well established, and offering palliative care when repeated curative interventions fail is generally regarded as the standard of care. Textbooks on palliative care discuss a wide range of somatic conditions, but psychiatric disorders barely get a mention (6). Perhaps this is because it is more difficult to determine when psychiatric treatment is futile. Prognoses are more uncertain, and there is often disagreement about the true goals of treatment.

Nevertheless, the complexity of psychiatry should not be used to justify withholding palliative care from patients who are suffering and, over time, have neither benefited from nor desired further curative treatment. Several indicators can be considered in making such a judgement: repeated treatment attempts with little or no effect on symptom reduction, adverse effects that outweigh benefits, poor adherence, frequent use of coercion, persistently low quality of life and lack of patient motivation.

Ethical and practical challenges

Palliative psychiatry entails a number of challenges, the first of which concerns the patient's right to self-determination. Many patients with severe and long-term mental illness are not considered competent to consent to curative treatment, which is often cited as justification for initiating interventions against their will. This makes collaboration on shared goals difficult. A palliative shift in approach therefore requires a nuanced assessment of capacity to consent, where it must be assumed that patients are capable of formulating their own palliative goals even if they are not competent to consent to decisions about their underlying illness. This allows for greater autonomy and genuine patient involvement during the palliative phase.

Another challenge is implementing palliative psychiatry in a way that does not leave patients feeling they have been let down or that all hope is lost. Many of the most severely ill psychiatric patients have painful experiences of being let

down, and a palliative approach could easily be viewed in the same light. It must therefore be made clear that palliative care does *not* equate to an absence of treatment. Palliative care *is* treatment, and a palliative approach could allow these patients to receive care on their own terms. Although the palliative approach is often less resource-intensive than curative treatment, it is by no means cost-free. Resources will likely need to be reallocated from other psychiatric services through active priority setting of the most severely ill patients at the expense of those who are healthier (cf. the severity criterion), but reducing overtreatment would likely provide most of the necessary resources.

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A prerequisite for establishing palliative psychiatry within mental health services is the development of guidelines safeguarding the standard of care (7). Better clinical tools are needed to assess who might benefit from a palliative approach. This requires a solid evidence base. To date, no randomised or longitudinal studies on the effects of palliative approaches in psychiatry have been conducted. Hypotheses that palliative psychiatry can improve quality of life, reduce iatrogenic harm, clarify expectations and strengthen autonomy must be tested empirically. Furthermore, a key empirical question is whether a palliative approach can prevent suicide among patients with treatment fatigue and existential suffering. Thus, palliative psychiatry must be promoted as a research field with its own questions, methods and quality criteria.

Is psychiatry prepared?

Palliative care already appears to be common in psychiatry, though it is often initiated prematurely and applied inconsistently. For example, many patients with schizophrenia never get the opportunity to try the last-line treatment clozapine (an antipsychotic), which can lead to radical improvement, because many clinicians hesitate to use it for various reasons (8). This raises questions about whether psychiatry's curative approach is sufficiently proactive. Many patients with depression also do not have access to the available range of evidence-based treatments, such as transcranial magnetic stimulation (9). If palliative goals aimed at improving quality of life are introduced before curative interventions have been sufficiently explored, this can, in the worst case, lead to serious undertreatment. By taking palliative care seriously, psychiatry can avoid piecemeal approaches that settle for less than optimal solutions.

> ***«Palliative psychiatry does not involve introducing something entirely new; it is about giving a name to an existing practice in psychiatry»***

International surveys show that most psychiatrists already consider it necessary to offer palliative care (10, 11). However, the term 'palliative' often causes concern among patients and their families, probably due to misconceptions about what it involves. Hopefully, we have provided some important clarifications, and perhaps it may even be beneficial if the term still evokes some concern. After all, this is not a topic to be taken lightly. It should now also be evident that palliative psychiatry does not involve introducing something entirely new; it is about giving a name to an existing practice in psychiatry that deserves a more structured and systematic approach than is currently the case.

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