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Lean In, Don't Step Back: The Views and Experiences of Patients and Carers with Severe Mental Illness and Incurable Physical Conditions on Palliative and End of Life Care

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Abstract

People with severe mental illness (SMI) have a life expectancy of up to twenty years less than the general population and many live with incurable physical health conditions. Yet, they continue to experience barriers when trying to access palliative and end of life care (PEOLC). Little research has been carried out which includes the views and experiences of people with SMI, and this study presents the first findings which include people with *both* SMI and an incurable condition and their carers. It aimed to seek their views, and those of their carers, on their experiences and expectations of accessing PEOLC and to understand how PEOLC for people with SMI could be improved. Participants (5 patient participants and 3 carer participants) took part. Semi-structured interviews were carried out with each participant. A thematic analysis of the interview transcripts was undertaken led to the development of a conceptual framework and four overarching themes 1) Stigma and Prejudice – See Me, Not My Diagnosis 2) Hesitancy and Avoidance – Treading on Eggshells 3) Collaborators in Care – The Ignored Experts and 4) Connections - Leaning in, Not Stepping Back. This study presents the first accounts concerning experiences of palliative and end of life care, barriers to access and how care can be improved, from the perspectives of patients with both a SMI and an incurable condition and their carers. The findings illuminate an under-researched area of clinical practice and contribute rich understandings to future service developments and innovations.

Keywords: palliative care, end of life care, severe mental illness, patient experience, carer experience, psychosis, schizophrenia, dying,

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Conflict of Interest Statement

There are no personal conflicts of interest or any financial or personal relationships with other people or organisations that could inappropriately bias conduct and findings of this study.

Introduction, Background and Aim

This paper reports on a United Kingdom (UK) study to elicit views and experiences of a group of patients and their carers, with both severe mental illness (SMI) and incurable physical conditions. Previous studies have highlighted the need for research which includes views and experiences of patients and carers. This paper presents four overarching themes developed from a series of in-depth interviews. Views of palliative care and mental healthcare staff have been explored in earlier research by the authors (1).

The lack of attention paid to understanding the needs of people with SMI and incurable physical conditions has been highlighted (2,3) in the context of increasing focus on improving access to palliative and end of life care (PEOLC) services to marginalised groups (4,5). The experiences of people with SMI continue to be ignored and excluded in research, policy and practice developments.

Adults with SMI experience higher rates of physical ill-health and have a life expectancy 10–20 years lower than that of the general population (6). They are more likely to live in poverty or poor housing, or be homeless, and find it harder to stay in

employment than the general population. People with SMI also experience poorer physical health, partly due to higher rates of smoking, alcohol and substance misuse, and poor diet (6–8). They are often diagnosed with terminal conditions much later than the general population, often because of difficulties in accessing primary care services, communicating symptoms, lack of trust and not being taken seriously by healthcare staff. This leads to poorer prognosis due to delays in treatment being offered, compounded by poorer treatment compliance. It would therefore be expected that a higher proportion of people with a diagnosis of SMI would need to access PEOLC. A scoping review by Donald et al (2018) highlighted the need for further research on the barriers to accessing PEOLC for people with SMI, and also emphasised an absence of studies which involved patient and carer views or involved them in research design or evaluation. Most previous research consisted of retrospective case-note reviews, clinical records, single case studies and literature reviews. Earlier studies (9,10) included patients with SMI who were not terminally ill and asked about their end of life care needs and preferences. Research by the authors (1,11) identified an absence of the views and experiences of patients with SMI and an incurable physical health condition and their carers. To date there are no previous studies which include participants with both SMI and an incurable or terminal illness. This is considered the first study which captures the views and experiences of this marginalised group.

Terminology

The term severe mental illness or SMI has been used in this paper as an umbrella term to describe illnesses such as schizophrenia, bipolar disorder, chronic depression, personality disorders and other mental illnesses or conditions where ‘psychological problems are so debilitating that functional and occupational ability is impaired’ (insert ref). People experiencing SMI likely to require treatment in specialist mental health

services rather than in primary care. SMI is the commonly used term in the UK, however, other terms such as Serious and Persistent Mental illness (SMPI) or Chronic and Persistent Mental Illness (CPMI) are also used to describe this group of illnesses, particularly outside Europe.

Participants

Participants were sought from two large mental health trusts (one urban and one semi-rural serving a combined population of c. 1.2 million people) and a group of five local hospices in England, UK. Patient participants with a diagnosis of a serious mental illness, who were also patients in secondary mental health services and who had a diagnosis of an incurable physical health condition were eligible. Carers of people who met these criteria were also eligible to take part. Patient participants were invited to identify members of their informal care network to participate. Five patient participants and three carer participants took part in the study. Four participants were male (all were patients rather than carers) and four were female (one patient and three carers). None were from Black, Asian or Minority Ethnic (BAME) backgrounds. Five participants were aged between 50-64, one was between 20-24 and two aged between 40-50. All patient participants were cared for in community-based secondary mental health services and all had experience of inpatient psychiatric admissions. Only one had experience of hospice care. Patients consented to their mental health care co-ordinator being informed of their participation. All participants had capacity to consent to participate, patients lacking mental capacity were excluded from the study. The lead researcher is an experienced mental health practitioner or psychotherapist and each participants capacity to take part was assessed by their care co-ordinator and the lead researcher at the time of consent to participate.

Ethics

Ethical and governance approval was granted by each participating organisation, including the NHS Research Ethics Committee and the researcher's University Ethics Committee. Pseudonyms were used to protect the identity of participants. All participants gave written consent to participate in the study.

Methods

Each participant took part in a semi-structured interview between November 2017 and March 2018. Interviews were arranged at a time and location comfortable for the participant including within the home, within hospice and within mental health trust locations. Due to the exploratory nature of the study, and lack of previous research involving the patient group, semi-structured interviews were chosen to allow the participant to share the breadth of their experiences and retain a focus on their views and experiences in relation to the scope of the study. Interviews were audio-recorded and transcribed.

A thematic analysis (12) was undertaken, using a collaborative, reflexive approach. Themes were developed through iterative analysis of the interview transcripts. Interviews were carried out (JJ). JJ carried out an initial analysis and coding of the transcripts. JJ, NH and DP reviewed and refined the initial coding. All authors verified the final themes and conceptual framework.

Findings

Four overarching themes were developed from analysis of the interview data (Insert Figure 1). Participants are referred to as either patient participants or carer participants where a distinction is important.

Insert Figure 1 Conceptual Framework

Theme 1 Stigma and Prejudice ‘See Me, Not My Diagnosis’

Patient participants expressed a desire to be treated as an individual and not defined by their diagnosis. Prejudice towards people with mental illness is well documented (8,13–18) and the patient participants experienced the same prejudice as others living with mental ill-health. However, their status as dying or terminally ill patients, added an additional layer of stigma, particularly from mental health services.

All of the patient participants interviewed described a complex history of mental and physical health conditions and had multiple co-morbid physical and mental diagnoses which impacted upon their ability to engage with healthcare services.

All participants described a lack of understanding of the impact of physical ill-health from mental healthcare staff, and of how mental health issues affect their ability to attend health appointments or make new relationships with healthcare teams. This lack of understanding led some to hide or mask their symptoms because they felt their needs would not be met or understood.

‘I have been sectioned before, but I can’t go in again, I can’t, they wouldn’t be able to cope with this [colostomy] there and if I got an infection or my bloods were out, they wouldn’t know, they don’t have those kind of nurses there, I have to stay at home, I have to, I just say I am ok when they [mental health team] come...I’d like to talk to them, but I’m scared they will think I am [mentally] unwell again’ (Lorna)

Patient participants also highlighted the need for early referral to enable relationships to be made when someone is mentally well as below.

‘They need to get to know you when you’re quite well [mentally] so they can support you when you aren’t so well’ (Lorna)

All of the patients and carer participants expressed frustration at not being treated holistically and with healthcare teams focusing on their speciality and not considering the relationship between different health conditions, symptoms and medications. All

participants highlighted a lack of understanding in healthcare staff of the relationship between physical and mental health and expressed a desire for greater integration of mental and physical healthcare services. One patient participant, who had an incurable lung condition said

'they [specialist respiratory team] just want to talk about your physical health and they think your mental health is just going to be sorted. They don't want the overlap if you know what I mean? There is a definite "we deal with this, they deal with that" and it's the same with the mental health [team]...it's really fragmented like your life is in boxes and they never interlink...it just makes me feel like I am living five different lives at a time' (Jordan)

Most participants did not expect all clinical staff to have specialist knowledge, but they expressed a need for professionals to feel confident enough to ask questions and retain curiosity, and to trust that people with mental illnesses are able to express their needs.

'so it's not necessarily about them having lots of information about mental health or whatever, and in some ways it might be better if they didn't as they wouldn't make assumptions...really it's about them having the skills and confidence to see you as an individual and to ask you about your difficulties' (Colin)

All participants described multiple experiences of encountering stigma and prejudice when accessing healthcare. This included experiences of diagnostic overshadowing (15) which they described as feeling 'fobbed off'.

'I did get to see my GP and I said to him I think I have a problem with my prostate and he said don't be silly you're not old enough, I'm not even going to examine you.....ten weeks down the line, I found out I had terminal prostate cancer' (John)

'two years, two years I was up and down that hospital...the doctor just kept sending me back and it was awful' (Lorna)

Previous feelings of stigmatisation impacted on willingness to try to access palliative care when they became incurably ill and towards a tendency to minimise mental health symptoms or to adopt a less stigmatising diagnosis. Patient participants were very aware of a 'hierarchy of mental illness' where anxiety and depression are less stigmatised than psychotic or personality disorders.

'I don't say I have suffered psychosis, cos I knew, I've opened up before and I wasn't treated very nice, you know what I mean? It [depression] feels less evil than schizo-affective disorder...it's that first word "schizo" it puts everyone in the frame of mind "oh don't upset her" ...but were are not axe-wielding psychos' (Lorna)

Within this theme, patient participants highlighted their own awareness of the fear that their mental health diagnosis prompted in the clinical staff they encountered, in both physical and mental health settings. In addition, the compartmentalising of different aspects of health needs contributed to an overwhelming feeling of being seen as a set of conditions or labels, rather than as a person with a need for kindness, compassion and understanding. This compounded poor experiences of healthcare at a time when good support was needed.

Theme 2 Hesitancy and Avoidance 'Treading on Eggshells'

Previous research highlighted the fear that professionals hold about 'saying the wrong thing' or de-stabilising people with SMI by talking about issues surrounding PEOLC, death and dying (1,2). Clinical staff reported avoiding having conversations or answering questions with people with mental illness, sometimes due to their own lack of confidence or because of beliefs they held about risk or mental capacity.

Patient and carer participants were very aware of this hesitancy and avoidance but felt very strongly that it was unhelpful for them and often left them feeling a sense of invisibility or abandonment. On this point, they described a feeling of clinical staff

‘treading on eggshells’ around them. Patient participants described an avoidance of sharing diagnosis or prognosis information.

‘So they told me I had cancer, but they didn’t tell me how bad...they didn’t tell me anything, you know nobody sat me down and talked to me...they gave me some pamphlets and told me to go home and read them and that’s basically how I found out [about terminal prognosis] (John)

In addition, patient participants described feeling patronised or fobbed off in relation to understanding their diagnosis.

‘I had things said to me like “well we won’t do any more tests because tests can be confusing” which I thought was a bit patronising and a bit of a strange comment to make’ (Colin)

In addition to poor experiences of being diagnosed, patient participants highlighted lack of onward referral to palliative or end of life care services (PEOLC). Only one patient participant was accessing PEOLC, attending a hospice day service. He had been referred not by his mental healthcare co-ordinator or oncology clinicians, but by a housing support worker who recognised his isolation and need for support. All participants also highlighted their own lack of knowledge of service provision, the lack of supportive family or care networks to advocate for them and the need for all healthcare staff, including mental health teams, to have better knowledge of what PEOLC services are available, and how to refer patients.

‘Actually, I don’t know what support is out there, it would be helpful for us to know, you know, what we can do is...even if it isn’t for now, so we know when we do need it, and I could bring it up with mum’ (Jane)

One participant, who had accessed hospice care, described how important it was for him.

'I didn't know they [hospice] did a day centre or respite. It's been a lifeline for me as I have no family or friends really, just my neighbour, but here I am, part of the group like everyone else' (John)

The study highlighted how isolated people with SMI are and how they may lack support, particularly from family, so access to PEOLC services is vital if compassionate, dignified care is to be provided at the end of life.

Previous research by the authors (1) highlighted that clinical staff felt concerned about upsetting or de-stabilising patients by talking about death, dying, advance care planning and other issues surrounding working with terminally ill patients who have SMI. In this study, all participants were clear that these fears lead to avoidant behaviour, which exacerbates negative feelings of abandonment or invisibility.

'So like the mental health team don't want to even acknowledge I have this [incurable lung condition], they just want to talk about my mental health and it's like they don't even see me...and the lung team gave me this book about what will happen to me but they won't refer me to a hospice or whatever, they think it will make me suicidal or something when it just makes me feel like no-one cares' (Jordan)

Patient participants also felt care could be improved by focusing less on assumptions of risk and more on talking with patients directly about their mental and physical health, PEOLC needs and expectations and addressing these questions earlier on in the care journey.

Theme 3 Collaborators in Care 'The ignored experts'

The role of a carer of a person with SMI and a terminal condition is complex and is often characterised by a long period of caring for the person's mental health needs prior to physical health diagnosis. For the patient participants, their care networks were limited with only one having a carer to nominate to take part. Patient participants highlighted that their care networks are often non-traditional, including other service

users, staff and community members in addition to family members. Family relationships can be difficult or absent and participants highlighted the importance of talking to clinical staff about who is in their care network and who they would like to be involved in their PEOLC planning.

The carer participants highlighted the depth and breadth of the caring role and discussed conflicts within the role, which can be conceptualised as the role of the 'ignored expert'. On one hand, carer participants felt they were expected to be experts, full time advocates, expert in conditions and treatment and able to provide intimate and personal care. On the other hand, they described being ignored consistently by healthcare staff and services. Communication with carers was poor and often they felt they were labelled as 'part of the problem'. This left them feeling with both a burden of care and frustration at being excluded from decision making and planning.

'There are so many people involved, it's a full time job, no-one speaks to anyone else and you are left to do all that' (Julie)

'purely through my tenacity...everything he needed, like day release or day support...I had to fight for' (Bridget)

Carers experience of receiving support was very negative. The knowledge they had about the person they were caring for was often ignored as below.

'They can be dismissed or not taken with any kind of authority by professional people. They have a similar experience to me...they can be overlooked and dismissed or excluded and I've wanted them included...they can have, very much a similar experience to the patient' (Colin)

Carer participants also highlighted a need for professionals to share information with them about accessing available services. They highlighted the need for earlier referral to PEOLC to ensure proper support could be in place and relationships made before the very end of life. The need for respite, symptom control and hospice at home services

was particularly highlighted, and support to avoid emergency admissions to hospital was particularly important for people with mental illness.

'No-one mentioned palliative care, even when they said the treatment wasn't working...we haven't had any information about hospice care certainly...I thought that was just for the last bit really to be honest'
(Jane)

Carer participants also discussed the gap between support received at the point of diagnosis and the very last weeks of life, including the need for support throughout this period so that services could be put in place as care needs increased. Carers, like patient participants, also highlighted that people with mental illness often benefit from longer periods of time for appointments and to build relationships, so flexibility is important in providing patient-centred care. They also highlighted the lack of collaborative working between primary care, secondary mental health services, medical specialists and palliative care.

The carer participants had all experienced negative personal impacts due to their caring role. Carers had left employment, delayed medical and surgical treatment for themselves, carried out night-time care and not been able to take holiday or spend time with their own families whilst caring. They described the emotional strain of their caring role, but also the guilt of using respite services (if they were available) or simply considering respite provision.

'I did have to put him in respite when my step-daughter got married in Cyprus. And it was the worst week of my life, let alone his, I felt I had abandoned him by putting him in...it was probably the worst thing I ever did' (Bridget)

Carer participants reflected that caring for someone with complex mental and physical health needs is a difficult and all-consuming role. Whilst none of the carers interviewed wanted to stop or wished they had not carried out their caring role, they all reflected at

length on the negative impact of being a carer and the lack of support available to carers. They felt this was exacerbated by caring for someone with multiple vulnerabilities due to their complex mental health diagnosis and terminal condition.

Theme 4 Connections ‘Leaning in, not stepping back’

The fourth, and most significant, theme highlights patients and carers experiences of abandonment by services, poor connection and inaccessibility of services and how care could be improved. All participants highlighted, the response of mental health services in particular to their diagnoses of life-limiting and terminal conditions. Patient and carer participants experience was one of abandonment and disconnection. They felt that mental health services did not understand the importance of their [MH services] own role in supporting their service users when they were physically ill, and much less so once their physical health conditions were deemed incurable. Some patient participants had experienced being discharged from services without discussion or onward referral to palliative or hospice care.

‘They just wrote to my GP and said I was being discharged from the [Community Mental Health Team] ...after thirty years, thirty years...I needed help even more once I knew about the cancer, not less’ (Lorna)

None of the patient participants had been given information about palliative care by their mental health teams and felt that their mental health clinical teams did not understand what services were available or how to access them. Participants who had not been discharged described a withdrawal of support as highlighted below.

‘So in a way it was a discharge from the service...once the medication stopped, we had no contact with the team. It was a case of phone us if you need us’ (Bridget)

Patient participants also described what it felt like to tell non-mental health healthcare staff about their mental health needs. They described a similar feeling of disconnection, withdrawal and ‘stepping back’.

‘there is that prejudice when you tell them “Oh I have problems with my mental health” you know, they sort of, they take a defensive step back...we [people with mental illness] haven’t got the black death, as soon as you mental health people go ‘eurghhhh’ you know, and that is more scary than having a mental illness’ (John)

All participants highlighted how important consistency of care was, particularly when coping with an incurable physical illness, and the impact of doing so on their mental ill-health. They highlighted how difficult and frightening it is to be diagnosed, to have to deal with new healthcare staff and appointments and cope with treatment. The lack of co-ordinated support was described as problematic by all participants.

What patients and carer participants valued was less about structure, policy or procedure and more about relationships with clinical staff as summarised by one patient participant’s experience of services withdrawing at a time when they were needed most.

‘I just needed them to lean in, when I most needed them to lean in, they stepped back’ (John)

Both patient and carer participants talked about the importance of care planning, referral processes and other ‘organisational’ procedures but attunement was most important.

Positive care experiences were those where healthcare professionals attuned to the needs of the patient, rather than their own needs (or fears) or those of the service (adhering to rigid referral or access criteria for example).

‘It would have been too much at the start...but I mentioned it in passing after while of coming here and he (day hospice nurse) came back half an hour later with a pile of leaflets and it wasn’t like “here you go, plan

your own funeral”, he sat down and talked me through it, and said you don’t have to be worried, you can do this quite easily you know’ (John)

John was the only participant who had accessed hospice care, and he talked about the importance of things moving at his pace.

‘I came to see the art therapist at first, and he introduced me to a nurse after a few weeks. Then I came to visit day hospice and they explained I could come for respite or symptom control if I needed to...they helped me when I had to re-home the dog too. I think I’d like to be here at the end you know, which I never would have thought of before’ (John)

Others expressed a desire for staff to check-in regularly and to be able to bring in, or refer on, to other services, particularly palliative care, when needed.

‘I need someone to check in with me and see if I am OK as then when things progress they can flag up what’s available where cos I don’t know, how am I supposed to know, and what’s the point of having a care co-ordinator if they don’t co-ordinate anything?’ (Lorna)

Carers spoke of the importance of some flexibility to usual procedures to allow relatives to avoid anxiety provoking waits and becoming physically unwell. It was often small changes which had a big impact. The things which made a difference to both patients and carers were often small adaptations or flexibilities, which were subtle but impactful as mentioned below.

‘the GP is very good and now Mum does have that support when she’s not well, so she has to go into hospital regularly [for infections to be treated] because she is having chemotherapy and you’d have to ring the GP, then it would be 12 hours in A and E and then she’d be admitted but we’d have to wait hours for a bed, where now she can just ring the ward and go straight in which is so much better for her mental health’ (Jane)

Discussion

Overwhelmingly, participants' accounts of their experiences highlighted an absence of care co-ordination, disconnection between services, patients, carers and healthcare staff.

The interviews offered rich descriptions of multiple experiences of poor care, gaps in care, lack of collaborative working, underpinned by prejudice and stigma surrounding both death and mental illness. Participants' accounts were compounded by earlier experiences of prejudice and stigmatisation when trying to access healthcare services and highlighted the lack of confidence in clinical staff from all disciplines when working with dying, mentally ill patients and their carers.

This study sought to explore and understand the views and experiences of people experiencing both SMI and an incurable condition on palliative and end of life care. Findings show that what is important to patients and carers is the attitude and approach of clinical staff, not necessarily their knowledge or the policies and procedures of the organisations they work within. That is not to say that addressing structural and organisational issues is not important. Ensuring that clinical staff have the knowledge and skills about mental health issues and what forms good PEOLC for people with SMI is important. However, simply providing information, without focusing on changing attitudes is not enough. The ability of clinical staff to see the person behind the labels is critical to improving care experiences. Patients and carers experienced poor care throughout their journey from diagnosis to the last weeks of life. Their accounts were sadly characterised by feeling abandoned, unheard, ignored and feared by clinical staff and services throughout the healthcare system. Participants felt they were viewed as unable to be included in care planning and decision making and described the feeling of being excluded as causing more distress than talking about and planning for their own death and end of life care.

The concept of 'leaning in, not stepping back' is central in addressing the issues raised in this study. What emerged in the course of listening to patient and carer accounts of care, both positive and negative, was the importance of attitude as well as knowledge. A clinician's ability to sit with their own uncertainty, remain open to both asking questions and hearing answers was crucial to positive experiences of care. Patients were deeply aware when staff 'stepped back'. What was apparent when 'leaning in' was present, was that small acts had a significant impact. Stopping to ask a question, showing curiosity, being able to listen to a patient's fears, experiences or views doesn't cost anything, it doesn't rely on service re-design or additional resources – it is about an ability to be alongside people who might be different to ourselves and retain professional curiosity. This relies on having a feeling of safety. If staff feel unsafe, out of their depth or fearful, it is impossible to 'lean in' and attune to patient's needs.

Further research is required to continue to understand the needs of people with SMI and incurable conditions, and their carers and families. This research should involve patients and carers. Aside from this study, there is currently very limited published research (insert Knipperberg ref) which includes the views and experiences of the patient group.

Also highlighted in the study, was the need to move towards more holistic care planning and delivery, which holds the mental health and physical health needs of the patient and their support network in mind.

People with severe mental illness experience inequality in almost all areas of society, and particularly in healthcare. Dying is a universal experience, and whilst it is hoped that preventative work will begin to address the low life expectancy of people with SMI, people will continue to require PEOLC at some point. The ability of those providing and co-ordinating that care, requires us to see beyond the labels and diagnoses, and see

and hear the person behind them. As John described, this is about a shift in attitude and behaviour.

*'I just needed them to lean in, when I most needed them to lean in,
they stepped back'*

Strengths and Limitations

One of the strengths of this study is that it is one of the first studies to include the voices of people living with both SMI and an incurable, physical illness. This patient group can be hard to identify and recruit due to their complex health needs but the researcher's experience in both mental health and palliative care services was useful in understanding the patient group and recruiting to the study.

The main limitation was the number of participants within the study and the lack of cultural diversity within the cohort. This was in some ways surprising due to the diverse communities within the locality, however, as previous research has shown, there are significant barriers to inclusion within both mental health services and palliative care services to people from BAME backgrounds (insert refs.) Future research which aims to include a greater diversity of participant, and a greater number of experiences is recommended.

A reflection on the impact of the Covid-19 global pandemic

Covid-19 has caused all health and care settings, including mental health services, to have to consider the end of life care needs of service users in an unprecedented way.

The impact of the pandemic has amplified discussions about health inequalities, the care of dying people, the role of families and carers at the end of life and the need for greater psychological support for patients, families and carers as well as for clinical staff. It is important that the learning from the pandemic is taken forward and not lost as services return to more usual practices.

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