



Navigating the Minefield: Managing Refusal of Medical Care in Older Adults with Chronic Symptoms of Mental Illness

Cathal O’Cionnaith ¹
Anne PF Wand ¹⁻³
Carmelle Peisah ^{3,4}

¹Older Persons Mental Health Service, Jara Unit, Concord Centre for Mental Health, Concord Repatriation General Hospital, Concord, NSW, Australia;

²Specialty of Psychiatry, Faculty of Medicine and Health, University of Sydney, Sydney, NSW, Australia;

³Discipline of Psychiatry, Faculty of Medicine, University of New South Wales, Sydney, NSW, Australia; ⁴Capacity Australia, Crows Nest, NSW, Australia

Purpose: The purpose of this case series is to illustrate the complexity of considerations across health (physical and mental), ethical, human rights and practical domains when an older adult with chronic symptoms of mental illness refuses treatment for a serious medical comorbidity. A broad understanding of these considerations may assist health care professionals in navigating this challenging but common aspect of clinical practice.

Case Presentation: Three detailed case reports are described. Participants were older adults with an acute presentation of a chronic mental illness, admitted to a specialized older persons mental health inpatient unit (OPMHU) in an Australian metropolitan hospital. Significant comorbid medical issues were detected or arose during the admission and the patient refused the recommended medical intervention. Data extracted from patients’ medical records were analyzed and synthesized into detailed case reports using descriptive techniques. Each patient was assessed as lacking capacity for healthcare and treatment consent and did not have relatives or friends to assist with supported decision-making. Multifaceted aspects of decision-making and management are highlighted.

Conclusion: There are multiple complex issues to consider when an older adult with chronic symptoms of mental illness refuses treatment for serious comorbid medical conditions. In addition to optimizing management of the underlying mental illness (which may be impairing capacity to make healthcare decisions), clinicians should adopt a role of advocacy for their patients in considering the potential impact of ageism and stigma on management plans and inequities in physical healthcare. Consultation with specialist medical teams should incorporate multifaceted considerations such as potentially inappropriate treatment and optimum setting of care. Equally important is reflective practice; considering whether treatment decisions may infringe upon human rights or cause trauma.

Keywords: treatment refusal, human rights, capacity, ageism, psychiatric

Introduction

The poor physical health and premature mortality of people with mental illness compared to people without mental illness are well established.¹⁻⁴ Several factors contribute to this disparity in health. These include (i) lifestyle factors (eg smoking, inactivity)⁴⁻⁶ compounded by medication-related factors (eg metabolic syndrome and obesity);⁷ (ii) the impact of symptoms of mental illness (eg disorganization, paranoia, avolition) on help-seeking behaviour;⁸⁻¹¹ (iii) systemic factors such as poor integration between mental and physical health services^{8,10} and (iv) social inequity (eg homelessness, poverty) leading to poorer access to care.^{10,12} The risks

Correspondence: Anne PF Wand
Older Persons Mental Health Service, Jara Unit, Concord Centre for Mental Health, Concord Repatriation General Hospital, 109 Hospital Road, Concord, NSW, 2139, Australia
Tel +61297678940
Fax +61297678944
Email a.wand@unsw.edu.au

of morbidity and mortality are magnified in older adults with mental illness, especially those with chronic symptoms. This group are more likely to have multimorbidity^{13,14} and additional ageing-related barriers to accessing healthcare such as sensory and cognitive impairment,¹⁵ reduced mobility and access to transport,^{16,17} higher service needs mismatched with more limited financial resources¹⁷ and poorly coordinated physical healthcare services.¹⁴ These barriers to care are compounded by ageism in health. A recent comprehensive systematic review of ageism across seven million participants over five continents, revealed significantly worse health outcomes due to ageism in over 95% of the studies across 11 health domains, including the mental-illness domain.¹⁸ Older adults with mental illness often face the unique problem of “double stigma”; negative attitudes towards both old age and mental illness.^{19–22}

Additional factors underpinning the poor physical health of people with mental illness who present for medical care are treatment refusal and lack of decision-making capacity.²³ Treatment refusal can occur in the presence or absence of decision-making capacity.²⁴ The core elements of capacity are the ability to understand the information relevant to the decision, the ability to use or weigh that information as part of the decision-making process, and to communicate the decision.²⁵ Common law establishes that an adult is presumed to have the capacity to consent to or refuse medical treatment unless that presumption is rebutted.²⁶ However, capacity may be affected by symptoms of mental and physical illness, emotional state and cognition, which may fluctuate over time and resolve with treatment and support.^{27,28} With psychosis, for example, there may be symptoms such as delusional beliefs leading to mistrust of clinicians or denial of illness.²⁸ Chronicity of symptoms may pose additional barriers to restoring capacity.

Thus, some people with mental illness may refuse medical treatment at a time when they lack capacity to give informed (competent) consent or refusal.^{23,28} Unless the clinician recommending medical treatment recognizes the patient’s lack of capacity, their treatment refusal may be accepted at face value. This may fuel ageist behaviors and attitudes such as lack of therapeutic zeal, demonstrated in clinician responses to medical illness amongst older adults.²⁹ Thus, a person lacking capacity may be deprived of important medical care for a variety of reasons,^{23,26} adversely affecting his/her health and, potentially, lifespan.

Although refusal of medical treatment in people with mental illness is not uncommon in clinical practice, there is relatively little guidance from the literature about holistic management of the issue. Rubin et al (2018) proposed a 7-question algorithm to provide clinicians with an ethical framework for managing treatment refusal in patients lacking capacity.³⁰ Case reports of medical treatment-refusal have been described in the literature, highlighting issues which may arise including impaired decision-making capacity, stigma and competing ethical principles^{9,23,31–37} although older adults, particularly those with mental illness, are underrepresented. Similarly, none of the aforementioned studies consider the specific ethical and human rights challenges pertinent to older adults, nor do they consider the combined interplay of medical and mental illness, and practical issues facing clinicians in the setting of treatment-refusal.

The aim of this case series is to illustrate the complexity of considerations across health (physical and mental), ethical, human rights and practical domains when an older adult with chronic symptoms of mental illness refuses treatment for a serious medical comorbidity.

Materials and Methods

Study Setting

Participants were admitted to an Older Persons Mental Health Unit (OPMHU) in a public Australian metropolitan hospital in 2020. The OPMHU is a 30-bed specialized inpatient unit designed to deliver acute mental health care to persons aged 65 years and older. Older adults with a range of mental health problems may be admitted including people with mood disorders, psychosis, severe behavioral and psychological symptoms of dementia, adjustment disorders, substance misuse, and personality vulnerabilities. The unit is staffed by specialist OPMH-trained medical, nursing and allied health care professionals and offers a range of biological, psychotherapeutic, social, rehabilitation and diversional therapies.

Case Selection

Participants were older adults admitted with an acute presentation of a chronic mental illness and significant comorbid medical issues which were detected or arose during the admission and for which the patient refused the recommended medical intervention. Three illustrative cases were chosen which highlight the complexity of considerations

for management across health (physical and mental), ethical, human rights and practical domains.

Data Collection

Data extracted from patients’ medical records were analyzed and synthesized into detailed case reports using descriptive techniques. REDCap (a secure, password-protected, web-based data management tool designed for research) was used to capture and store de-identified research data.^{38,39} De-identified research data were entered into REDCap from the patients’ electronic medical records. A second researcher verified that the data transferred were accurate and complete.

Results

Names of patients have been modified and replaced with a pseudonym. Pseudonyms are followed by an asterisk (eg Rose*) the first time they appear in the text.

Case 1

John* is a 70-year-old man with schizophrenia who lives in a residential aged care facility (RACF) [nursing home/long-term care facility]. He was referred for an involuntary admission to the OPMHU by the consultation-liaison psychiatry (CLP) team for management of psychosis, after being admitted to a general hospital for hemoptysis. Medical imaging had demonstrated a spiculated lung lesion, highly suspicious for malignancy. Additional medical issues included bilateral lower limb oedema of uncertain cause, and an unexplained mobility decline. John had refused further investigations and management of these issues. The medical team had recommended discharge with a plan for outpatient investigations.

The CLP team concluded that John’s psychotic symptoms impaired his decision-making capacity in relation to treatment and follow-up of his numerous medical issues and therefore recommended inpatient treatment of his psychosis. On the OPMHU he demonstrated grandiose and persecutory delusions, including beliefs that he could control weather events and that he was being targeted by free radicals and radio waves. These delusions had been present for many years despite treatment with depot antipsychotics. Cognitive testing with the Rowland Universal Dementia Assessment Scale (RUDAS)⁴⁰ revealed mild impairment (23/30). He was commenced on fortnightly risperidone depot.

Despite treatment of his psychotic symptoms, John continued to lack capacity for treatment consent. He believed

his hemoptysis was due to poisoning at his RACF, and that he could not have cancer as he was no longer symptomatic. He refused the recommended investigation (a positron emission tomography [PET] scan) due to fears of radiation poisoning. John also demonstrated instability of choice with respect to investigations and management.

In Australia, a range of laws exist to guide appointment of substitute decision-makers for adults unable to give consent.^{25,41} As John was socially isolated with no informal substitute decision-maker, he was appointed a Public Guardian. A Public Guardian in New South Wales (NSW), the jurisdiction of this case, is a public official appointed by the Guardianship Division of the NSW Civil and Administrative Tribunal⁴² with powers for substitute consent for health care and treatment for people with decision-making disabilities including, as in John’s case, authority to override the person’s objections.²⁵

Venous ultrasound of John’s lower limbs revealed a unilateral deep vein thrombosis (DVT). Treatment was complicated by John’s intermittent refusal of therapeutic enoxaparin injections, which resulted in temporarily switching treatment to oral rivaroxaban as this was more acceptable to John, where possible trying to respect his will and preferences and minimize the over-riding of such. No cause was found for John’s mobility decline. He engaged intermittently with physiotherapy, although did not progress to his pre-morbid level of walking independently likely due to sarcopenia from prolonged inactivity.

In liaison with respiratory medicine and with consent from the Guardian, after considering the risks and benefits of investigation and the potential severity of John’s underlying lung condition, a decision was made to proceed with an endobronchial ultrasound (EBUS) of the mediastinal lymph nodes and a biopsy of the lung lesion. Consent for pre-anesthetic sedation was also provided, given John’s refusal. Notably, John later communicated that he had been metaphorically “raped” by the involuntary invasive medical procedure.

Biopsy results of John’s lung lesion revealed aspergillosis rather than malignancy. He assented to a course of an oral antifungal. There were residual, but improved, symptoms of psychosis on risperidone. After 13 weeks John was discharged to his RACF with follow-up appointments for management of his aspergillosis and DVT.

Case 2

Chris* is an 84-year-old man with schizophrenia who lives alone and has no family or friends. He was admitted

involuntarily to the OPMHU for an exacerbation of his chronic psychotic symptoms. Chris had persecutory delusions which incorporated his neighbors, the department of public housing, police and health services. Consequently, he had a life-long mistrust of health services and avoidance of care. Treatment with risperidone was commenced.

Multiple previously unknown comorbidities were found on routine screening at admission, including anemia with severe vitamin B12 and iron deficiencies. Cognitive testing revealed moderate impairment (RUDAS = 17/30), possibly secondary to nutritional deficiencies. It also transpired that a pituitary lesion, suspected to be a macroadenoma, was identified the year before, although Chris had not followed-up with investigations.

Chris refused recommended management of these issues. He was assessed as lacking decision-making capacity with regards to health care and treatment consent. He had persecutory delusions, accusing the treating team of dishonesty and feigning his pathology results in order to appear superior to other hospitals. He also demonstrated illogicality, concrete thinking, perseveration and poor recall for medical information.

Chris was appointed a Public Guardian for health care and treatment consent. The Guardian consented to Chris having an intravenous iron infusion and a course of vitamin B12 injections. Parenteral administration was recommended by the gastroenterology team due to the severity of his nutritional deficiencies. Midazolam sedation was administered prior to the iron infusion to facilitate safe administration given Chris’ ongoing refusal of treatment. He was subsequently administered a course of seven vitamin B12 injections over two weeks. A colonoscopy to investigate his nutritional deficiencies was cancelled because of his refusal to take the bowel preparation. An endoscopy revealed atrophic gastritis.

Chris was not amenable to magnetic resonance imaging (MRI) of his brain or visual field testing to investigate the pituitary lesion. However, there was biochemical evidence of hypogonadism, with associated long-term risk of osteoporosis/fracture, in addition to pituitary hemorrhage. These risks were contrasted with the risks of testosterone replacement and invasive surgical intervention. Upon further discussion with endocrinology and the Guardian, and taking these risks into account, it was concluded not to proceed with further intervention.

Chris’s distress and preoccupation with his persecutory delusions attenuated during the admission. He was frustrated by the length of his admission and declared the

numerous imposed injections (iron, vitamin B12 and risperidone) unnecessary and unjust. Following a 9-week admission, Chris was discharged home with follow-up appointments for his atrophic gastritis and pituitary lesion.

Case 3

Rose* is a 70-year-old woman with schizophrenia living in a boarding house. She had no informal substitute decision maker. She was admitted involuntarily to the OPMHU for treatment of an acute exacerbation of her chronic psychotic symptoms. These symptoms included delusions of pregnancy, delusions about her identity (having multiple people living inside her) and grandiose delusions that she, along with her “squires”, could cure diseases and fight wars. She was cognitively impaired, scoring 21/30 in the Montreal Cognitive Assessment (MOCA).⁴³ Rose was trialed on two different antipsychotic depots (paliperidone and zuclopenthixol) over the course of the admission.

During her admission, Rose had a mechanical fall which resulted in a left neck of femur and left distal radius fractures. Her treatment refusal for surgery was based on a delusional interpretation of her injuries, namely that they were incurred after being pushed over when out working with squires and did not result in fractures. She also believed her medical records had been falsified. On this basis she was found to lack capacity for treatment consent.

She was transferred to the orthopedic ward for operative management of her fractured hip. Consent was given for the operation by the Medical Superintendent according to Australian Mental Health Laws.⁴¹ Her distal radius fracture was managed conservatively.

Rose was required to remain non weight-bearing (NWB) for a period of six weeks postoperatively. She required a 1–1 nurse to effectuate this as she continued to deny having fractured her hip. She was transferred back to the OPMHU for ongoing treatment of her psychosis and completion of her NWB period. Rose was reviewed by the orthogeriatric team but not transferred to the rehabilitation unit due to a lack of beds, her preference to stay in the OPMHU, and concerns about disruptive behaviors. Although she continued to deny she had had a fracture or an operation, she was cooperative with physiotherapy and occupational therapy provided on the OPMHU. A Public Guardian was appointed to evaluate further healthcare decisions.

Rose had a second fall, this time sustaining an open fracture of her left distal radius. This was repaired surgically, with consent from her Guardian. Due to her multiple

low trauma fractures, the geriatrics and endocrine teams recommended treatment for osteoporosis. Rose’s Public Guardian provided consent for a zoledronic acid infusion and for investigation and management of emergent rectal bleeding/iron-deficiency anemia. A colonoscopy revealed hemorrhoids and she was treated with an iron infusion.

The intensity of Rose’s psychotic symptoms improved over the course of the admission on zuclopenthixol. Following a seven-month admission she was discharged home with follow-up appointments for her osteoporosis and hemorrhoids.

Discussion

These three cases of older adults with chronic symptoms of mental illness and medical comorbidity illustrate the significant complexity and breadth of decision-making and care provision. In each case the person had long-standing mistrust of health services, neglect of health and refusal of treatment. Each person was socially isolated without relatives/friends and lacked capacity for health care and treatment consent. These are not unusual impediments to treatment and care for those with chronic mental illness, mandating a nuanced approach that considers a range of ethical and human rights challenges, while practically facilitating optimal mental and physical health treatment.

Medical Futility and Potentially Inappropriate Treatment

Although frequently used by clinicians in their decision-making,^{44,45} including in reference to patients unable to make decisions,⁴⁶ the concept of medical futility is controversial and there is no generally accepted definition.^{44,46} This is the crux of the problem with futility. Although one simplified definition is “a clinical action serving no useful purpose in attaining a specified goal for a given patient”,⁴⁷ such definitions have been criticized, as determination of treatment futility is subjective and based on the values of the clinician,^{45,48} what is futile for one clinician may not be for another.⁴⁹ This is particularly so in the context of ageism and discrimination in health for older adults with mental illness. Although the concept of potentially inappropriate treatment is often preferred,⁵⁰ the issues at stake are similar, namely a balance between several issues, including benefit and harm, consistency with personal values or ethical principles, and availability of resources.⁴⁴

These issues were key to decision-making in two of the cases. For example, Chris’s suspected pituitary

macroadenoma was not further investigated or managed given there was a low chance of achieving meaningful benefit, which would outweigh the burden of potentially invasive surgical treatment, including the risks of requiring lifelong post-operative prednisone or desmopressin in a patient never adherent to oral medication. This contrasts with the management of Chris’s nutritional deficiencies. Although he was asymptomatic, the anemia could affect his mood, energy and cognition, and may have heralded an underlying gastrointestinal malignancy; all potentially treatable. Thus, consent was sought from the Guardian to investigate and manage nutritional deficiencies. The expertise of specialist teams was important in determining whether to seek consent for each recommended intervention.

Feasibility of procedure is also relevant here. Treatment refusal may render certain procedures impractical, even with coercive measures. For example, a planned percutaneous core biopsy of John’s lung lesion was cancelled as it required intraprocedural cooperation. Chris refused to drink bowel preparation, so his colonoscopy was also cancelled. Similarly, while it was considered “futile” by some medical teams to investigate John’s suspected lung malignancy given the unfeasibility of delivering chemotherapy or radiotherapy to someone refusing treatment, the uncertainty of the diagnosis mandated advocacy from the OPMHU team, to investigate and diagnose what transpired to be aspergillosis, a treatable condition. Otherwise, with a presumed malignancy, he may have been considered palliative, influencing future treatment decisions. This highlights the potential subjectivity of futility as a concept,^{45,49} the potential danger of assuming the futility of treatment in a “difficult” patient refusing treatment, and may also reflect stigma.

Stigma and Ageism

Stigma towards people with mental illness exists among clinicians across healthcare disciplines,^{9,51–54} resulting in poorer quality of physical health care.^{8,51–56} Stigma potentially influenced the initial decision not to investigate John’s lung lesion. It is also possible that Rose was declined inpatient rehabilitation after her hip fracture surgery due to stigmatization by clinicians. Although lack of beds was cited, she was not placed on a waiting list. Concerns about her being disruptive on a rehabilitation ward and her preference for OPMHU (despite demonstrated lack of capacity regarding the fracture) were

prioritized over provision of usual comprehensive rehabilitation care post-fracture.

Patient age may also influence the management of treatment-refusal. Ageism has been defined as the stereotyping of and discrimination against individuals or groups based on their age, and has been identified as a priority for improving healthcare.⁵⁷ Ageism may be reflected in the clinical practice and decision-making of clinicians,^{17,58} affecting the quality of health and social care that older adults receive.^{17,57,59} Patient age may have affected decision-making in the presented cases. For example, it seems surprising that John was initially to be discharged to his RACF from the medical ward, given his multiple uninvestigated medical issues. Would this have occurred with a younger person? Perhaps the complex combination of his age, difficult attitude, stigma towards people with mental illness, refusal of treatment (despite demonstrated lack of capacity), and presumed futility of investigation or management, resulted in him being recommended an impractical and unrealistic pathway in the form of out-patient care. Clinicians may not have been conscious of these influences in their decision-making.

Autonomy, Beneficence and Non-Maleficence

In the presented cases the ethical principle of beneficence was prioritized over non-maleficence and patient autonomy.⁶⁰ Each patient made choices about their healthcare, which were largely driven by psychotic symptoms, that would inevitably result in pain, suffering and premature mortality. The identified lack of capacity for treatment consent led clinicians to intervene in the patient’s best interests according to appropriate legal frameworks.⁴¹ It is possible that other clinicians, recognizing the potential distress to the patient in compelling them to have the refused medical investigation or treatment, would have prioritized non-maleficence over beneficence. Which approach is right? It could be considered negligent or manifest therapeutic nihilism to accept at face value a decision made without capacity when there are serious health implications. Conversely, to knowingly cause distress through imposing an invasive intervention on a person refusing it, even though they lack capacity to consent or refuse it, is ethically questionable and directly contravenes trauma-informed care, a paradigm underpinning the development and delivery of mental health services internationally.^{61–64} John was clearly traumatized by

having treatment against his will, metaphorically equating his lung biopsy to “rape”. Chris too emphasized that the injections administered (including vitamin B12) were a violation of his rights. There is considerable literature supporting their perspectives, highlighting the trauma experienced by mental health consumers in receipt of healthcare services,^{63,65} with clear implications for future engagement. In the presented cases, attempts were made to minimize the degree of potential inflicted trauma when choosing interventions. For example, John’s delusional beliefs about radiation poisoning influenced a decision to cancel a planned PET scan (which involved administration of a radioactive tracer) and instead proceed with an EBUS/biopsy.

Human Rights

The Convention on the Rights of Persons with Disabilities (CPRD) was passed by the United Nations in 2006⁶⁶ with the aim of providing a legally binding international framework for protecting the rights of people with disabilities (including people living with chronic mental illness).⁶⁷ Key here is Article 25, the right to enjoyment of the highest attainable standard of health without discrimination on the basis of disability. The embodiment of this right was actualized by ensuring access to equitable diagnosis and treatment of John’s lung lesion and other medical comorbidities described.

However, other rights are at stake in these cases. The ongoing violation of human rights in psychiatric settings^{68,69} and of older adults^{70–72} is well documented. The coercive treatment practices illustrated can impact on human rights by violating autonomy.^{73,74} With regard to international mental health and guardianship legislation, Article 12 of the CRPD (“Equal Recognition before the Law”) has been interpreted as needing a shift away from traditional paternalistic substitute-decision-making (with a focus on “best interests” and risk reduction), towards supported decision-making, favoring the rights, will and preferences of the individual with disability/mental illness in all circumstances.^{67,75} The absence of a relative/friend to support decision-making and help determine pre-existing wishes/preferences in these cases was noted.

Furthermore, a supported decision-making approach (as opposed to the substitute-decision making approach adopted in these cases) may be at odds with other important human rights.⁷⁶ For example, without the application of relevant guardianship and mental health laws⁴¹ in the presented cases, the patients would have likely suffered

premature morbidity and mortality, contravening the aforementioned Article 25 and Article 10 (the right to life) of the CRPD.

Decision-Making Capacity

Each of the presented cases was assessed as lacking capacity for health care and treatment consent. Inability to understand information about the nature and effect of their medical condition and proposed management was the main factor impairing capacity. All three patients did not believe the information provided about their medical condition, secondary to various delusions. In addition, cognitive impairment including impaired reasoning, perseveration and poor recall affected Chris's ability to understand and retain information given. Although mild cognitive impairment was noted in the other cases, it did not affect decision-making; an important consideration in capacity assessments.²⁵

The starting point is the Common Law principle of presumption of capacity for all adults, regardless of diagnosis.²⁵ There should be valid reason to rebut such presumptions, such as relapse of mental illness, to warrant a capacity assessment, and the assessment should occur in the context of a specific decision needing to be made.²⁵ It is for this reason that we cannot presume anything about the decisional capacity of any of such patients until assessment. Furthermore, restriction of autonomy should be as brief as possible and, where feasible, efforts should be made to assist a person to regain capacity.^{31,77} Notably in Australia, guardianship and administration orders are time-limited with compulsory review embedded within the legislation.²⁵ This is particularly relevant for mental illnesses such as depression or bipolar disorder which may have a relapsing remitting course, where capacity may be regained on treatment of the mental illness.^{31,78} Capacity may also be regained with diminution of acuity of symptoms in chronic schizophrenia.

Setting of Care

Older adults admitted to acute psychiatry inpatient units are frequently found to have significant comorbid physical illnesses that complicate patient care.⁷⁹ Furthermore, some people with mental illness often access mental health services as their first and only contact with the health system.⁸ Thus, psychiatric admissions may facilitate opportunistic medical contact in patients who have unaddressed physical illnesses or have avoided healthcare services. For Chris in particular, his OPMHU admission

resulted in the opportunistic detection of multiple unrecognized medical co-morbidities, which otherwise would have likely remained undiagnosed.

In the presented cases, much of the OPMHU admission duration was focused on delivering medical rather than psychiatric care (eg awaiting guardianship approval and procedure dates, facilitating post-procedure recovery/rehabilitation). There are ethical implications of extending the stay of involuntary patients in a locked mental health unit in order to focus on their medical care.

People with comorbid mental and physical illnesses may also be admitted to general hospitals, potentially presenting practical difficulties, particularly if the patient is disruptive and refusing care.⁸⁰ General healthcare staff may have limited skills to manage people with cognitive disorders⁸¹ or mental illness,⁸² which can impact provision of holistic care.

Although in these cases the OPMHU was perhaps a more practical setting for addressing physical health issues than the general hospital, it may not have been the best location for efficient specialist multidisciplinary medical care. The resulting longer length of stay likely compounded distress in patients already refusing treatment. Combined medical-psychiatry units are a potential solution, the goals of which include improving physical and psychiatric care, reducing stigma, and increasing the cost-effectiveness of inpatient stays by decreasing length of stay and readmissions.⁸³ They have been especially beneficial for older adults with complex behavioral, medical and psychiatric symptoms as can occur in delirium.⁸⁴

Clinical Implications: The Way Forward

This case series highlights the complexity and breadth of issues to be considered when an older adult with chronic symptoms of mental illness refuses treatment for serious medical comorbidity. Although some of the discussed management considerations are echoed elsewhere in the literature,³⁰ our study (to our knowledge) represents a first in focusing on holistic management of treatment-refusal in this particular population, with wider ethical, practical and human rights considerations.

The inherent variety of opinions and ethical perspectives in such complex cases may understandably result in clinician uncertainty and anxiety. Clinical ethics committees have emerged in general hospital settings as independent bodies who provide a formal mechanism for dealing with complex ethical issues.⁸⁵ Their goals include protecting patient rights and providing clinicians with advice and expert opinion

regarding issues such as provision of treatment against a patient’s wishes.⁸⁵ They are beneficial in terms of improving satisfaction and reducing moral distress among clinicians, and may lead to changes in management plans.⁸⁶ Peer review groups in psychiatry are another helpful means of discussing the inherent uncertainty and complexities of these cases.⁸⁷

Education and training of clinicians to better understand and manage the complexity of treatment refusal is needed. Research has highlighted poor awareness among clinicians of human rights frameworks,^{71,72} and inadequate knowledge of capacity assessment²⁴ and relevant legislative frameworks to manage treatment refusal.^{24,88,89}

Study Limitations

There are some potential limits to the generalizability of this study’s findings. Small case series, while rich in data and able to capture a complex array of issues, are by definition not generalizable.⁹⁰ Moreover, by focusing on a particular theme, case series are not inclusive. For example, in this series, all three cases had chronic symptoms of psychosis and some had co-morbid cognitive impairment, thus the study did not demonstrate the impact of other types of mental illness (such as depression and anxiety) on treatment refusal. Nonetheless, the broader considerations highlighted in this study are applicable to all older adults with chronic symptoms of mental illness.

None of the cases had a supportive care network, which does not reflect the diversity of older adults’ social networks, and the presence of which may have facilitated a supported decision-making approach^{91–93} to management and assisted in establishing the person’s pre-existing wishes and preferences.

Finally, this study took place within the Australian healthcare system. While it is beyond the scope of this case series to consider the myriad guardianship, administration and conservatorship legislation across all jurisdictions, Australia is bound by both Common Law and international human rights frameworks such as the CRPD. Notwithstanding variable legislation and application of the CRPD across various jurisdictions, there are widely applicable considerations relevant to all persons with mental health conditions including ethical and human rights of autonomy, equitable access to quality health care and respect for will and preferences, and Common Law principles of presumption of capacity.^{25,94}

Conclusion

There are multiple complex issues to consider when an older adult with chronic symptoms of mental illness refuses treatment for serious comorbid medical conditions. In addition to optimizing management of the underlying mental illness (which may be impairing capacity to make healthcare decisions), clinicians should adopt a role of advocacy for their patients in considering the potential impact of ageism and stigma on management plans and inequities in physical healthcare.^{1,3} Consultation with specialist medical teams should incorporate multifaceted considerations such as potentially inappropriate treatment and optimum setting of care. Clinicians require training in assessing decision-making capacity and navigating complex legislative frameworks relevant to treatment refusal. Equally important is reflective practice; considering whether treatment decisions may infringe upon human rights or cause trauma. Management of treatment refusal in older adults requires embracing the complexity and weighing up the overlapping ethical, practical and human rights factors for each individual, and seeking peer review and clinical ethics expertise when needed.

Ethics Approval and Informed Consent

Ethical approval for the study was obtained from Sydney Local Health District’s Human Research Ethics Committee (Reference number CH62/6/2020-125). This study was conducted in accordance with the Declaration of Helsinki. Written consent for inclusion in the project and for publication was obtained from each of the patient’s legally appointed guardians, as none of the patients had capacity to provide informed consent. However, all patients assented to their inclusion in the study.

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