The Content of Psychiatric Advance Directives: A Systematic Review

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Objective: Psychiatric advance directives (PADs) enable users of mental health services to express their treatment preferences for future mental health crises. PAD completion rates remain low despite high rates of interest among service users and empirically confirmed benefits of their use. A systematic review of service users' preferences regarding the content of PADs could be a valuable resource for clinicians and policy makers and might help reduce barriers to PAD implementation.

Methods: A systematic review concordant with PRISMA guidelines was conducted. CINAHL, Cochrane, EMBASE, PsycINFO, MEDLINE, PubMed, SCOPUS, and Web of Science databases were searched up to July 2, 2021. Included articles contained original empirical data on service users' preferences regarding the content of PADs or a document analysis of existing PADs. Studies were analyzed thematically, and a narrative synthesis was conducted. The Mixed Methods Appraisal Tool was used to assess the methodological quality and risk of bias of the included studies.

Results: The search yielded 4,047 articles, 42 of which were eligible for inclusion. Six themes emerged (most of which included subthemes): signs of crisis, general treatment approach, preferences regarding the treatment setting, treatment preferences, coercion, and social instructions.

Conclusions: The concern that PADs may be unclear or incompatible with practice standards was not confirmed. Service users generally included clear, comprehensible, and clinically relevant information in their PADs, often providing underlying reasons for their preferences. These reasons were related to previous adverse effects of medication and personal experiences with hospital admissions.

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Psychiatric advance directives (PADs) are documents that enable users of mental health services to express their treatment preferences for future mental health crises. They can be created by the service user alone or with the support of at least one other person. The latter are often referred to as facilitated PADs. Specific PAD subtypes include crisis cards, which contain only basic crisis management information, and Ulysses contracts (also referred to as self-binding directives), which contain advance instructions to override service users' treatment refusals during mental health crises (1).

The legal status of PADs varies across countries. Explicit legal provisions exist in many Western countries, such as Australia, Belgium, Canada, Germany, Ireland, the Netherlands, Scotland, and various states in the United States (2). Very few Asian countries have legal provisions for PADs, with India being a notable exception (3). The legal force of PADs varies even across jurisdictions with legal provisions for PADs. In many jurisdictions, including U.S. states and jurisdictions within Australia, mental health professionals can override or disregard PADs when doing so would be in the service user's medical best interest (4, 5). In other countries, such as Germany, mental health professionals are under a legal obligation to honor specific treatment refusals expressed in valid PADs, even if doing so would not be in the service user's medical best interest (6).

Service users report that PADs contribute to the promotion of autonomy (7–10) and well-being (11–13), prevention of harm (7, 8, 10, 14), and improvement of the therapeutic relationship (14–16). A systematic review and

HIGHLIGHTS

- Users of mental health services generally included clear, comprehensible, and clinically relevant treatment preferences in their psychiatric advance directives (PADs).

- Only a very small minority of service users used or would use PADs to refuse all psychiatric medication in advance.

- The content of PADs was generally compatible with professional practice standards.

meta-analysis of randomized controlled trials found that of all the interventions included, only PADs significantly reduced involuntary hospital admissions (17). Various bodies of the United Nations have recognized PADs as a form of supported decision making and have emphasized that the United Nations Convention on the Rights of Persons With Disabilities requires further implementation of this instrument (2, 18).

Although studies have consistently found a high interest in PADs among service users (10, 19–21) and high endorsement rates among professionals (22, 23), the implementation of PADs has progressed slowly. Moreover, PAD uptake remains low (19, 24) because of various barriers to PAD completion (25).

Several barriers relate to the content of PADs. Service users indicate that PAD completion is too difficult (11) and that they do not know what to write in their PADs (23, 26, 27). Mental health professionals may be hesitant to support the implementation of PADs because they are concerned that PAD instructions may be unclear (28, 29) or incompatible with practice standards (23, 29, 30). Professionals also have raised the concern that service users could use PADs to refuse all psychiatric treatment (6, 31, 32).

Most of these barriers can be addressed. Service users, for example, have indicated that they would appreciate guidance in the completion of PADs in the form of information materials and templates (16, 33, 34). Apart from a few promising initiatives (e.g., by the National Resource Center on Psychiatric Advance Directives at https://nrc-pad.org) (33, 35), however, guidance on PAD completion is lacking.

The primary aim of this systematic review was to describe and systematize what mental health service users write in their PADs and think should be included in them. The secondary aim was to provide a resource for the development of guidance for PAD completion, such as information materials, templates, handbooks, and training modules.

METHODS

A systematic literature review was carried out in accordance with PRISMA guidelines (36). The protocol for this systematic review was developed in accordance with these guidelines but was not registered.

Eligibility Criteria

We included articles that contained original quantitative or qualitative empirical data on mental health service users' preferences regarding the content of PADs or document analyses of existing PADs.

We excluded articles that included only people with dementia, people with mild cognitive impairment, or older adults without mental disorder; contained only data on advance directives in the context of end-of-life decision making or somatic health conditions; did not contain an analysis of service users' preferences separate from other stakeholder groups; or were not available in English, German, or Dutch. Data on service users' views on the benefits and challenges of PADs were analyzed in a companion systematic review (37).

Search Strategy

We selected search terms on the basis of the inclusion criteria established through common variations of the relevant terms "advance directive" and "psychiatry." The search terms were adapted from a previous systematic review (38) and were established through agreement between two authors (M.S. and E.B.). The basic search string was adapted to the requirements of each database to search title, abstract, and keywords. CINAHL, Cochrane, EMBASE, PsycINFO, MEDLINE, PubMed, SCOPUS, and Web of Science databases were searched. No restrictions were imposed, and all years and publication types accessible were allowed. The search was conducted on October 15, 2020, and updated on July 2, 2021. The bibliographies of all articles included were screened for additional references, but this screening did not yield any further studies. (The full search strategy for the PubMed database is available in an online supplement to this review.)

Selection of Articles

Results from all database searches were added to an EndNote library. We removed duplicates by using EndNote X9 and then through manual searches and removal. Titles, abstracts, and full texts of retrieved records were screened by two authors independently by following the aforementioned inclusion and exclusion criteria (E.B. and M.S. for titles and abstracts and A.-S.G. and E.B. for full-text articles). An overall concordance of 93% was achieved. Disagreements were discussed between two authors for titles and abstracts (E.B. and M.S.) and among three authors (A.-S.G., E.B., M.S.) for full-text articles, until consensus was reached.

Data Extraction and Quality Assessment

Data on study characteristics were extracted and tabulated by three authors (A.-S.G., E.B., M.S.). Characteristics included country, methods, sample characteristics, type of PAD, and information about whether having a PAD was an inclusion criterion for the study.

We assessed the quality of studies with the Mixed Methods Appraisal Tool (MMAT) (39), which provides quality criteria for qualitative, quantitative, and mixed-methods study designs. The studies contained in this review included quantitative, qualitative, and mixed-methods designs. We preferred the MMAT over appraisal tools specifically for qualitative research or content analysis because the MMAT enabled us to assess the quality of all included studies with the same tool. A score of 1 (criterion was fulfilled), 0 (criterion was not fulfilled), or 0.5 (partial fulfillment) was assigned to each item, resulting in a quality score ranging between 0 and 5 for each method used in the studies. Studies with a qualitative or quantitative score of ≤2 were given less weight in the presentation and interpretation of

the results. We did not exclude studies on the basis of the quality assessment because the aim of the review was to describe and systematize the full spectrum of PAD contents, and data from studies with lower methodological quality were likely to enrich the full data set for the review. A heterogeneous subsample of eight studies was independently rated by two authors (A.-S.G., E.B.), and discrepancies were discussed to ensure adequate interrater reliability. All remaining studies were rated by either A.-S.G. or E.B.

Data Synthesis

Empirical data on service users' preferences regarding the content of PADs were synthesized in a narrative fashion informed by the Economic and Social Research Council Methods Programme "Guidance on the Conduct of Narrative Synthesis in Systematic Reviews" (40). After familiarization with the data, three authors (A.-S.G., E.B., M.S.) established an initial list of thematic categories. These initial categories were also informed by our prior knowledge of the literature on PADs. We analyzed relevant data thematically and coded the data by using MAXQDA 2020, starting with the initial categories and refining the code system inductively through emerging codes. A subsample of six articles was coded independently by two authors (A.-S.G., E.B.). Differences were compared and discussed among three authors (A.-S.G., E.B., M.S.) to establish consensus for further analysis. All other articles were analyzed (by A.-S.G., E.B., or M.S.). Changes in the coding system were discussed among these three authors. The final codes were tabulated and integrated into a narrative synthesis. Because the aim of this review was to describe and systematize primarily qualitative data on the content of PADs, meta-analysis was not deemed appropriate.

RESULTS

Study Selection and Characteristics

The initial systematic literature search yielded 4,047 records (see the PRISMA flow diagram in the online supplement). Of the articles identified, 39 were eligible for inclusion. The updated search yielded three additional articles, resulting in 42 articles being included (7–9, 11, 13, 14, 16, 20, 26, 27, 30, 33, 34, 41–69). (Study characteristics of all included articles are provided in the table available in the online supplement; the characteristics refer only to parts of the studies that were relevant for this review.) The studies included were published between 1999 and 2021 and were conducted in 11 countries, primarily the United Kingdom (N=12, 29%), the United States (N=11, 26%), New Zealand (N=4, 10%), and India (N=4, 10%). Two studies (45, 49) were published in German and were analyzed by German native speakers (A.-S.G. and E.B.); all other studies were published in English. Nineteen studies were identified as qualitative, 13 as quantitative, and 10 as mixed-methods studies. The sample sizes relevant to our research question ranged from 6 to 932 (total N=4,633). Units of investigation were either PAD

documents or mental health service users providing information about PAD content. The most common inclusion criteria were a diagnosis of schizophrenia or related disorders, bipolar disorder, depression, or serious mental illness in general. All participants were ages ≥18 years.

Twenty-six (62%) of the 42 articles contained descriptive data on PAD content. In 21 of the 26 studies (7–9, 14, 42, 43, 45–47, 50, 52, 53, 55, 58–61, 64, 65, 68, 69), PADs were created in the context of the study or the larger research project. The remaining five studies (11, 49, 56, 57, 62) examined PADs that were created outside of a research setting. Sixteen (38%) of the 42 studies (13, 16, 20, 26, 27, 30, 33, 34, 41, 44, 48, 51, 54, 63, 66, 67) contained "hypothetical" accounts of PAD content, meaning that service users were asked what they or others would write in a PAD or what information they thought should be included in PADs. Accordingly, having a PAD was not an inclusion criterion for these studies. One study (11) contained both descriptive and hypothetical data but was categorized as descriptive. The descriptive studies were differentiated further into studies examining facilitated PADs and studies examining nonfacilitated PADs. PADs were categorized as facilitated if they were created by service users in consultation with at least one other person (e.g., a researcher, mental health professional, lawyer, or peer) or with the use of fully developed templates with predetermined answer categories. All other PADs, including those based on templates without predetermined answers, were categorized as nonfacilitated. Nineteen of the 26 descriptive studies (7, 11, 14, 42, 43, 45–47, 49, 50, 52, 56, 58, 60, 61, 64, 65, 68, 69) included facilitated PADs, and seven of the descriptive studies (8, 9, 53, 55, 57, 59, 62) included nonfacilitated PADs. Two of the descriptive studies on facilitated PADs (45, 58) examined crisis cards in particular, and one hypothetical study (67) focused on self-binding directives. In most hypothetical studies, the type of PAD was not specified.

The table available in the online supplement also lists the results of the quality assessment according to the MMAT. Some studies (26, 27, 44, 49, 53) had low quality (MMAT score ≤2) and were given less weight in the synthesis of findings. No studies were excluded on the basis of quality criteria.

Synthesis Findings: PAD Content

The content of PADs was categorized into six themes, which were further differentiated into domains and subdomains (Table 1): "signs of crisis," reporting on early warning signs, crisis triggers and symptoms, and strategies to prevent relapse; "general treatment approach," which included service users' requests to be treated with empathy and respect; "preferences regarding the treatment setting," encompassing requests regarding hospitalization and alternatives as well as the involvement of known health care personnel; "treatment preferences," including treatment according to professionals' advice, preferences regarding medication, preferences regarding electroconvulsive therapy (ECT) or

TABLE 1. Mental health service users' preferences regarding the content of PADs in the studies included in the systematic review[a]

Domain	Total N	Studies with hypothetical PADs[c] (N)	Descriptive studies[b]			References
			N	PAD was facilitated (N)	PAD was not facilitated (N)	
All studies	42	16	26	19	7	
Theme 1: signs of crisis	21	4	17	13	4	
Early warning signs, crisis symptoms, and crisis triggers	21	4	17	13	4	7, 8, 11, 16, 20, 33, 43, 45–47, 52, 54–56, 58–62, 65, 69
Strategies to prevent relapse	4	0	4	4	0	46, 47, 58, 61
Theme 2: general approach—empathic, respectful, and dignity-preserving treatment	9	1	8	5	3	7, 43, 46, 47, 51, 55, 59, 62, 65
Theme 3: treatment setting preferences	30	8	22	16	6	
Treatment location	29	8	21	15	6	
General request for and consent to hospitalization	11	2	9	8	1	11, 42, 47, 48, 55, 58, 60, 64–66, 69
Request for certain hospitals and wards	17	3	14	9	5	7–9, 14, 27, 41, 45, 46, 49, 50, 53, 55, 59, 60, 64, 65, 67
Refusal of certain hospitals and wards	7	1	6	4	2	8, 47, 55, 58, 64, 65, 67
Request for hospital alternative (e.g., home treatment, outpatient treatment)	11	5	6	3	3	16, 20, 27, 47, 48, 53–55, 59, 60, 64
General refusal of hospitalization	7	2	5	3	2	20, 43, 47, 50, 54, 55, 62
Involvement of specific health care professionals (e.g., regular treating psychiatrist, general practitioner)	8	0	8	5	3	9, 45–47, 52, 55, 59, 69
Reasons for preferences regarding the treatment setting	9	1	8	5	3	8, 41, 46, 47, 55, 58, 60, 62, 64
Theme 4: treatment preferences	38	13	25	18	7	
Treatment according to the recommendations of the service user's psychiatrist	4	2	2	2	0	13, 42, 48, 60
Medication preferences	33	9	24	18	6	
General statements (e.g., current medication)	11	3	8	7	1	7, 13, 16, 45, 47, 49, 55, 56, 60, 64, 67
Request for specific medication	21	7	14	9	5	7, 9, 11, 13, 16, 20, 27, 33, 46, 47, 52–55, 57, 60, 62, 64, 65, 67, 68
Refusal of specific medication	25	7	18	14	4	7, 8, 11, 13, 20, 27, 34, 42–44, 46, 47, 50, 52, 54, 55, 57, 58, 60, 62, 64, 65, 67–69
Reasons for medication preferences	15	3	12	9	3	7, 8, 14, 16, 27, 34, 43, 46, 47, 50, 55, 60, 62, 64, 69
Preferences regarding ECT	20	6	14	9	5	
ECT request or consent	8	2	6	3	3	8, 9, 11, 13, 53, 60, 64, 66
ECT refusal	17	5	12	9	3	7, 8, 11, 13, 16, 27, 41, 42, 46, 48, 50, 52, 55, 60, 62, 64, 65

TABLE 1, *continued*

Domain	Total N	Studies with hypothetical PADs[c] (N)	Descriptive studies[b]		References
			PAD was facilitated (N)	PAD was not facilitated (N)	
Reasons for ECT preferences	6	1	5	2	3	7, 8, 41, 55, 60, 62
Other treatment preferences	9	2	7	4	3	
Request for other treatment (e.g., psychotherapy)	8	2	6	3	3	13, 47, 48, 53, 56, 59, 60, 62
Refusal of other treatment	3	0	3	2	1	47, 58, 62
Refusal of all psychiatric treatment or medication	14	3	11	10	1	
Yes	6	3	3	3	0	11, 13, 30, 47, 48, 50
No	8	0	8	7	1	7, 9, 42, 46, 60, 64, 65, 69
Instructions regarding somatic health conditions	8	0	8	6	2	8, 45–47, 55, 64, 65, 69
Additional information and well-being factors (e.g., being outdoors, creative activities, support to take medication)	19	5	14	9	5	7–9, 16, 20, 27, 34, 42, 43, 45–47, 54–56, 59, 62, 64, 69
Theme 5: coercion	21	6	15	10	5	
Strategies for deescalation and reduction of coercive measures	10	2	8	7	1	6, 9, 20, 43, 45–47, 54, 56, 64, 65
Preferences regarding coercive measures	15	6	9	5	4	
Consent to and ranking of specific coercive measures	8	3	5	4	1	8, 44, 46, 52, 54, 58, 64, 66
Refusal of specific coercive measures	6	4	2	1	1	7, 16, 20, 54, 55, 67
Refusal of all coercive measures	3	0	3	0	3	55, 59, 62
Reasons for preferences regarding coercive measures	2	0	2	1	1	55, 64
Theme 6: social instructions	29	9	20	13	7	
Social preferences	20	5	15	11	4	
Whom to notify as contact persons	18	5	13	10	3	11, 16, 20, 27, 33, 45, 47, 49, 52, 54–57, 59, 61, 64, 65, 69
Whom not to notify	12	3	9	5	4	9, 11, 16, 20, 47, 54, 55, 57, 59, 61, 64, 69
Support (e.g., support groups, cultural support)	7	3	4	2	2	20, 27, 47, 54, 55, 58, 59
Personal matters (e.g., finances, pets, dependents)	15	6	9	6	3	7, 11, 13, 16, 20, 34, 46, 47, 54, 55, 57, 62–64, 69
Information about nominated representative	8	4	4	1	3	8, 11, 16, 20, 44, 53–55

[a] References are listed for subdomains only; some subdomains may have overlap in cited references. ECT, electroconvulsive therapy; PADs, psychiatric advance directives.

[b] Studies primarily containing analyses of existing PADs. Hindley et al. (11), which contains both types of data in similar proportions, was classified as descriptive. The descriptive studies were divided into those in which creation of the PAD was facilitated by others (e.g., psychiatric and other professionals or peers) and those in which PAD creation was not facilitated.

[c] Studies containing primarily data about service users' responses to questions about what should be included in PADs.

other treatment, instructions regarding somatic health conditions, and well-being factors; "coercion," comprising deescalation strategies and preferences regarding coercive measures; and "social instructions," including information about contact and support persons, management of private affairs, and information about legal representatives.

The proportion of studies providing hypothetical or descriptive data is stated for each theme, domain, and subdomain (Table 1). Descriptive studies tended to report more extensive and detailed PAD content.

Theme 1: signs of crisis. In half of the articles (21 of 42) included, service users included in their PADs early warning signs, crisis symptoms, and triggers, as well as strategies to prevent relapse (Table 1). Common early warning and relapse signs were negative thoughts and emotions (45), irritability (55), aggressive behavior ("hitting my family member or pets") (60), as well as isolation and decreased communication ("I become depressed, moody, eat alone, and isolate myself from others") (58). Crisis symptoms included worsened tremors and shaking (46) or suicidal thoughts (56). The PADs frequently included crisis triggers, which were often relational (8, 43, 56) (e.g., "seeing friends and family whom [service users] did not wish to see") (43). Other crisis triggers were "seeing violence on TV and unpredictable behavior or environments" (55) and "extreme sensitivity to any form of criticism" (7). In several studies (46, 47, 58, 61), the PADs, all of them facilitated, analyzed listed strategies to avoid relapse and protective factors, such as "the need to reduce alcohol, focus on eating well, and get enough sleep" (47). In one descriptive study of participants with substance use disorders only, the content of the facilitated PADs consisted mostly of relapse indicators, such as social isolation or feelings of hopelessness, and instructions on what users and their personal network could do in these situations (61).

Theme 2: general treatment approach. Service users emphasized the importance of improved attitudes and conduct of professionals toward service users in their PADs in nine (21%) of the 42 studies (Table 1). Such statements were subsumed under a separate theme because they covered fundamental principles of human interaction and could be understood as a prerequisite for more specific treatment preferences. Except for one hypothetical statement (51), the data presented in this theme were descriptive. One emerging aspect was the wish to be met with understanding, empathy, and positivity (e.g., "the importance of clinicians' understanding that [service users] were experiencing difficult emotions") (47). Service users also asked in their PADs for improved communication with staff (e.g., wanting "to be understood and listened to, for the person not to be too reactive to what I am saying") (55).

Service users in six studies (43, 46, 47, 55, 59, 65) included in their PADs the request for respectful treatment or for their own involvement in their care. Examples included service users who reported "dishonest, dismissive, [and]

condescending" treatment during previous crises and who expressed "a desire to avoid similar interactions in the future" (43); in addition, these service users requested "open communication about treatment and plans" (55). In two studies, service users emphasized the preservation of their dignity, including privacy and human rights: 25 (32%) of 79 service users in one study (59) requested "improved human rights" in their PADs, and in the other study (55), three service users noted that they did not want their "privacy breached" (i.e., that private information not be widely shared and that specific people not find out about the details of their treatment).

Theme 3: preferences regarding the treatment setting. Service users in 30 (71%) of the studies included in their PADs preferences regarding the treatment setting or considered it important that PADs contain such preferences (Table 1). Many service users requested or recognized the need for hospitalization if necessary, with several users listing circumstances in which they wanted to be admitted to the hospital (e.g., "If I say I'm hearing voices, then a bed must be found") (47). Dropping below a specific body mass index threshold tended to be a reason for hospitalization among service users with anorexia nervosa (58). Notably, agreement to hospitalization occurred more in facilitated than in nonfacilitated PADs. Service users in all studies often listed preferred hospitals or wards, such as wanting to be in a facility near their family (46, 47). Conversely, service users often documented specific hospitals or wards to avoid revealing an aversion to state hospitals in an Indian (53) and a U.S. (64) study.

Many service users preferred alternatives to hospitalization, such as outpatient treatment (requested by 32 [43%] of 75 service users [60] and 57 [57%] of 100 service users [48] in two quantitative studies), home treatment (47), or community alternatives (16, 59). In two quantitative hypothetical studies, most service users disagreed with the statement that PADs would be used to refuse hospital admission in advance (20, 54). However, some participants expressed a strong preference against hospitalization in their PADs, although most of them added caveats such as "[I refuse] being put in hospital. I know that this is sometimes necessary; however, I would like this to be the last resort" (50). Across all 42 studies, only 13 (0.3%) participants used their PAD to refuse hospital admission under any circumstance (47, 50, 62). Except for one study (62), all these PADs were facilitated.

Many service users stated the reasons for their preferences, such as "I prefer being treated at home because when I am in hospital, I worry about my children," (47) or "[I] prefer to have my own room if possible because [I'm] fearful of others" (7). One woman wanted to be admitted to a single-sex ward to prevent herself from engaging in promiscuous sexual behavior (41). In several studies, past negative experiences and ill treatment were listed as reasons to avoid specific hospitals (8, 62, 64).

TABLE 2. Reasons for medication preferences in psychiatric advance directives provided by mental health service users in the studies reviewed

Reason	References
For specific medication refusals	
General negative side effects	7, 8, 43, 46, 60, 62, 64, 69
Confusion, not being able to think clearly, not being able to function	7, 8, 46, 64
Worsening of the illness	47, 55, 62, 64
Allergies, problems related to comorbid conditions	43, 46, 60, 64
Drowsiness, sedation, "feeling doped up," sleepiness	8, 60, 64
Ineffectiveness	7, 8, 64
Suicidal thoughts	7, 8, 62
Weight gain	7, 8
Motor restlessness, tremors, shaking, spitting	7, 8
Association with fearful memories of coercion	8
Impotence	8
Trouble sleeping (e.g., nightmares)	47
Risk for addiction	46
Avoidance of pain (e.g., injections)	62
For specific medication requests	
Effectiveness	8, 62

Preferences regarding health care personnel were common. These requests included that contact be made with service users' treating psychiatrist, other mental health care professionals, or their general practitioner and that they be included in their care (55, 69). Some service users wanted to be admitted or treated by their regular treatment team, stressing the importance of continuity of staff (47, 59).

Theme 4: treatment preferences. Service users in 38 (90%) of the studies included treatment preferences in their PADs or found it important that PADs include treatment preferences, usually concerning medication or ECT (54, 67), and they often provided reasons for these preferences (9, 46) (Table 1). In four studies (13, 42, 48, 60), some service users agreed in advance to be treated in accordance with the recommendations of their treating mental health professional, revealing especially high adherence to professional advice in an Irish study (13) and two Indian studies (48, 60). These four studies included only facilitated PADs.

Medication preferences: many service users listed their current medication (45, 47), and some stipulated that no major changes be made to it (49, 55), often providing plausible reasons related to a medication's effectiveness or past experiences of adverse effects (16). Others stated that they would be willing to try medications not listed in their PAD if

these eliminated adverse effects (64). Preferences ranged from general, such as a preference for oral medicine over injections (53, 62), to specific, such as a preference for the particular medications valproate (68) or risperidone (47, 68). One emerging theme was a dominant preference for second-generation over first-generation antipsychotic medications (62, 64, 68). Refusals also ranged from general preferences, such as for treatment without antipsychotic medication (67), to the refusal of specific medications. The most frequently refused medication was haloperidol, followed by lithium and chlorpromazine. Service users often provided detailed reasons for their medication preferences, mostly for medication refusals and seldom for medication requests. Table 2 provides an overview of frequent reasons and the studies in which they were provided.

Preferences regarding ECT: almost half of the studies (N=20, 48%) included data on service users' preferences regarding ECT (Table 1). In eight of these studies (7, 8, 13, 42, 46, 48, 60, 64), most service users refused ECT in their PADs. In some cases of ECT refusal, the caveat "only as a last resort" (55) or to avoid death (41) was added. Hypothetical perspectives on ECT were more positive, with usually a higher percentage of service users endorsing ECT in principle (11, 13, 66). Consent to ECT in PADs was much less common. Only six descriptive studies contained any endorsement of ECT (8, 9, 11, 53, 60, 64), and in all of these studies, only a minority of service users agreed to it in their PAD. Service users sometimes mentioned specific circumstances under which ECT should be administered (e.g., "When I have suicidal thoughts") (60). Some service users offered reasons for their ECT preferences. Sometimes these reasons were based on previous positive or negative experiences (e.g., "No ECT under any circumstances; [it] hasn't always helped me, and it impaired me to the extent that I could not do work properly") (55), and sometimes they were based on diffuse anxieties (e.g., "[My doctor] had mentioned ECT or something. It's like a two-headed monster, you don't want to know nothing about it. . . . I'm terrified of ECT") (7).

Other treatment preferences: the most common other treatment request regarded counseling and psychotherapy (13, 48, 53, 59, 60, 62), followed by the request for self-regulatory and occupational therapy (48, 56, 62). Refusals in this domain concerned group-based therapy (62), home treatment (47), and rigid restrictions (e.g., "I don't want my activities stopped and made into something to earn") (58).

Refusal of all psychiatric treatment: across all descriptive studies, only very few participants (N=12, 0.3%) recorded a refusal of all medication in their PADs (11, 47, 50), and none explicitly stated refusing all psychiatric treatment. Differences between hypothetical and descriptive accounts emerged, with hypothetical statements indicating a higher preference for or expectation of the refusal of all treatment in PADs (11, 13, 30) than was found in actual PADs (50, 65). Eight studies mentioned explicitly that none of the participants used the PAD to refuse all medication or treatment. Notably, none of the nonfacilitated PADs analyzed in the

studies included in this review contained a refusal of all psychiatric medication.

Instructions regarding somatic health conditions: other frequent components of PADs were instructions regarding assistive devices, such as contact lenses or dentures (64), and information on somatic health conditions, such as a history of blood clotting (55), diabetes (46), and allergies (47).

Additional information and well-being factors: the PADs analyzed contained additional information and well-being factors in several studies. Service users tended to request some kind of activation (e.g., "encourage[ment] to get 'out and about'") (55), most often in the form of social or creative activities or being outdoors (8, 45, 64). Other service users mentioned that they wanted to be allowed to withdraw and not communicate with others (43, 56), and some requested spiritual connection in the form of meditation, reading of religious texts (16), or visits from clergy (7). Some service users gave highly personalized instructions, such as having access to the open air because it had helped them in the past when experiencing "visions" (62). Another request occasionally included in PADs was the need for support to take medication (59, 62). Some service users included the wish to eat well (47) or specific dietary preferences (55). Studies with hypothetical accounts and studies with descriptive data did not significantly differ in content in this domain.

Theme 5: coercion. Service users in 21 (50%) of the studies included in their PADs information on deescalation and coping strategies to prevent or reduce the use of coercive measures as well as preferences regarding coercive measures themselves—should they be inevitable—or endorsed the inclusion of these preferences hypothetically (Table 1). In two of the hypothetical studies, the inclusion of deescalation strategies was endorsed by high majorities: 22 (96%) of 23 service users in one study (54) and 91 (83%) of 110 service users in the other (20). These strategies included reaching out to and connecting with others (43, 56), involving mental health professionals (45), being left alone (9), and help in the management of emotions (56, 64). In this context, one service user explained, "I don't want threats of an injection; I would like people to talk to me explaining the need to take medication" (47). Others requested changes in medication or additional medication as deescalation strategies (64).

Preferences regarding coercive measures were documented in both descriptive and hypothetical studies. A few service users used their PAD to consent to coercive measures (46, 58). Some agreed to specific coercive measures in advance, but they limited their use to specific situations, such as "treatment refusals associated with violence" (52). Service users in two studies (8, 64) provided a ranking from most to least preferred coercive intervention (chosen from a specified list in one of the studies [64]), whereby medication in pill form was most preferred, and seclusion plus restraint was least preferred. These preferences were often backed up by plausible reasons (64). In a study of service users with anorexia nervosa (58), six (15%) of 41 service users used their PAD to consent in advance to the use of a nasogastric tube. Service users also refused or requested specific coercive measures such as physical restraint and seclusion because of previous negative experiences with these or other measures (7, 55, 64). Data on refusals of specific coercive measures were found mostly in hypothetical studies. Some service users (N=48 of 3,665, 1.3%) across all descriptive studies refused all coercive measures (55, 59, 62); these three studies included only nonfacilitated PADs.

Theme 6: social instructions. Twenty-nine (69%) of the studies contained preferences regarding the inclusion of contact persons or other social instructions in PADs (Table 1). Most service users chose someone from their immediate family, such as their partner, parents, or siblings (56, 59, 61). Service users in hypothetical studies strongly supported the inclusion of information on contact persons in PADs (11, 20).

The inclusion of people who should not be notified or not be permitted to visit in case of hospitalization was less frequent, with at most one-third of service users recording such instructions in their PADs in three descriptive studies (55, 57, 64). Some explained their preferences, providing reasons such as having a past of exploitation and mistrust with family members (16).

Apart from specific contact persons, service users in some studies also requested social support in a broader sense, such as the involvement of family generally (58, 59), support groups, and spiritual support by clergy or nongovernmental organizations (55). Service users commonly included information about the care and management of their personal affairs in their PADs. This request usually meant naming specific people to look after and manage finances (7, 64) and accommodation (46, 57) (e.g., ensuring their home was secure [62]) or, less often, to take care of children, other dependent relatives, or pets (47, 64). Other personal matters included contacting their workplace or looking after their car (55).

Relatively few descriptive studies reported the inclusion of information about legal representatives in PADs (i.e., the person who makes decisions for service users should they lack competence to consent) (11, 55). By contrast, hypothetical PAD accounts from five studies (11, 16, 20, 44, 54) indicated high endorsement rates among service users for including the option to nominate a legal representative in PADs.

DISCUSSION

The findings of this systematic review indicate that service users use or would use PADs to document a wide range of preferences for future mental health crises across various domains. The included studies revealed a high variation of preferences among service users, indicating that preferences in PADs are highly personal. The broad scope and high

variation of preferences highlight the difficulty of providing personalized crisis care and, hence, underscore the need for PADs.

PADs were mostly established for people with a diagnosis of schizophrenia or bipolar disorder, followed by people with depression. They could also be used by people with personality disorders, anorexia nervosa, or substance use disorders, but the form and content of PADs should be tailored to their specific needs (43, 56, 58, 61).

Service users generally expressed clear, detailed, and clinically relevant treatment preferences in their PADs. They frequently stated coherent reasons for their preferences, often based on previous personal experience with hospital admissions and adverse effects of medication. Only a very small minority of service users in the reviewed studies reported that they used or would use PADs to refuse all psychiatric medication in advance. Accordingly, psychiatric professionals' concerns that PADs may be unclear (30, 31), may be incompatible with practice standards (6, 23, 31), or may contain refusals of all mental health treatment (16, 32, 34) were not confirmed. The findings of this review may, therefore, help to mitigate professionals' concerns regarding PADs, which form a key barrier to PAD implementation (25).

Most PADs analyzed in the reviewed studies were created in the context of research; in addition, the studies were often facilitated by researchers, professionals, peer experts, or independent facilitators. However, studies that analyzed PADs created outside of the research setting (11, 56–58, 62) or nonfacilitated PADs (55, 57) yielded comparable results. Even in a study that analyzed 55 PADs that had been presented at a tribunal (62), indicating previous clinical conflict, incompatibility with practice standards was not reported; moreover, no PAD contained an explicit refusal of all treatment.

The PADs examined showed significant variation in the scope and detail of their content. This variation appeared to be associated with the level of standardization of and guidance for the drafting process. The more topic suggestions and support service users received in the drafting process, the more specific and detailed the instructions tended to be (53, 55). Nonfacilitated PADs tended to contain less adherence to psychiatrists' recommendations, less explicit consent to hospitalization, no refusals of all psychiatric medication, and more refusals of all coercive measures (59, 62). The tendency of nonfacilitated PADs to limit professionals' latitude in medical decision making may increase the risk for moral dilemmas in future crisis situations, particularly when service users refuse interventions such as hospitalization, medical treatment, or coercive measures that service providers deem necessary to avoid harm to the service user. Such dilemmas could be avoided by offering service users support and guidance during the drafting process. Apart from the aforementioned differences, however, no notable differences between facilitated and nonfacilitated PADs were found. The scope and level of detail of nonfacilitated PADs were all in all comparable to those of facilitated PADs.

Moreover, given professionals' concerns regarding nonfacilitated PADs (22, 23), we note that none of the nonfacilitated PADs analyzed in the reviewed studies contained a refusal of all psychiatric medication (9).

Highly standardized PAD templates, however, can also unduly influence service users' decision making. This influence is especially relevant when templates contain unbalanced topic suggestions, biased information, or tentative questions (60). The challenge in the creation of templated PADs is to provide guidance without exerting undue influence. The results of this review can serve as a resource for designing PAD templates and topic guides for the facilitation process.

We note that a request for a general treatment approach based on understanding, empathy, and respect emerged as a prominent theme from the analysis. This finding suggests that service users see PADs not merely as a means to communicate isolated treatment preferences but rather as a complex intervention with an impact on the treatment process as a whole. This theme aligns with findings of an older review of conceptual frameworks underlying PADs (70). The prominence of this theme also suggests that many service users feel that they have not been treated with understanding, empathy, and respect in the past.

Hypothetical accounts of what service users would write in their PADs or what information they believe should be included in PADs generally aligned with descriptive accounts of the content of existing PADs. However, we observed notable differences in some domains. ECT refusals were less prominent in studies of hypothetical accounts than in descriptive studies, whereas refusals of all medication and specific coercive measures were more prominent in hypothetical than in descriptive accounts. One possible explanation for this observation is that preferences change during the PAD drafting process. Another possible explanation is a selection bias of studies in which PADs were created. It is difficult to draw solid conclusions from these findings because of the methodological heterogeneity of the studies included.

Another difference between hypothetical and descriptive accounts was that a large majority of service users in studies of hypothetical accounts endorsed including an option for the user to nominate a legally authorized representative in PADs, whereas relatively few PADs in descriptive studies contained information about a nominated representative. An explanation for this finding may be that in many jurisdictions the legally authorized representative is determined by independent legal criteria and cannot be nominated by service users. That service users highly endorsed the option to nominate a legally authorized representative in a PAD is of interest to policy makers.

To the best of our knowledge, this systematic review is the first to provide an overview of mental health service users' preferences regarding the content of PADs. The comparability of the data was limited by the heterogeneity of

the methodology and quality of the studies included. It was further limited by the fact that the studies were carried out in 11 different countries with different PAD regulations, examined different types of PADs, and included different subgroups of service users. Given our research aim and design, however, the heterogeneity in data collection and sources did not pose a limitation for our study. Because our aim was to describe the full spectrum of PAD contents, the heterogeneity of the data strengthens our findings and conclusions. The generalizability of our findings is limited by the fact that most PADs analyzed in the studies were completed in the context of a research project, and only five studies (11, 49, 56, 57, 62) analyzed PADs not created in this context. The findings of our review might thus not fully reflect the content of PADs encountered in everyday clinical practice. Generalizability is further limited by the fact that studies included in this review were carried out predominantly in liberal, affluent, and Anglo-Saxon Western countries with well-established mental health laws and mental health systems. Comparable findings in India tentatively suggest that findings of this review can be extrapolated to countries with other characteristics. More research on PADs in non-Western and low-resource settings is needed to draw more solid conclusions.

CONCLUSIONS

The findings of this review indicate that when mental health service users prepare a PAD, they document clear, comprehensive, and clinically relevant preferences regarding future mental health crises. Concerns of psychiatric professionals that PADs contain preferences that are unclear or incompatible with practice standards were not confirmed. Moreover, only a very small minority of PADs contained a refusal of all psychiatric medication, and none contained a refusal of all mental health treatment. The quality of the PAD content varied depending on the level of support service users received during the completion process. Facilitation during the drafting process may decrease the likelihood of ethical dilemmas during future crisis situations. The findings from this review may serve as the basis for the development of PAD templates and manuals for the facilitation process.

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Technology in Mental Health Column

Editor: Dror Ben-Zeev, Ph.D.

Psychiatric Services' Technology in Mental Health column focuses on technology-based or technology-assisted approaches in the assessment, treatment, monitoring, or prevention of mental health problems (e.g., mHealth or eHealth, decision support tools, wearable devices, social media, and training programs). Given the rapid pace of technology development, multiple stakeholders—policy makers, administrators, clinicians, and consumers of mental health services—stand to benefit from learning about novel approaches as they emerge.

The column is an ideal venue to expose readers to innovative technologies and innovative strategies for using existing technology to improve mental health outcomes in a timely manner. Submissions may include (but are not limited to) informed opinion pieces, conceptual papers, analyses of the state of the field, policy papers relevant to the use of technology, and first-person accounts from users of technology in mental health (i.e., patients, providers, and administrators). Empirical efforts (e.g., deployment in the context of real-world care, proof-of-principle studies) will be considered only if the findings are used to inform a "bigger picture" discussion that has broader implications for the field. Authors are encouraged to explore, debate, and demonstrate how to capitalize on and build new technologies that will redefine the field by generating new science and practice.

Submissions should include a 100-word abstract and three one-sentence highlights. Up to 10 references are permitted. The total word count (including abstract, text, and references) should not exceed 2,400 words—or 2,000 with a small table or figure. Tables, figures, and multimedia material may be submitted as an online-only supplement to the column. Please submit online at ScholarOne Manuscripts (https://mc.manuscriptcentral.com/appi-ps).