#### What does recovery mean to Jordanian mental health service users and 1

- their families? A descriptive qualitative study 2
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# 12 What does 'recovery' mean to Jordanian mental health service users

13 and their families? A descriptive qualitative study

Background: The concept of recovery in mental health has been extensively
documented in the Western context. Yet, little is known about this concept in the
Arab context, particularly in Jordan.

17Aim: The aim of this study was to explore the conceptuality of recovery in mental18health from the perspectives of both Jordanian service users and their families.19Methods: A qualitative descriptive design was used, and semi structured20interviews were conducted with 16 service users and 16 family members, selected21from three different mental health sectors in Jordan: Government, Military and22University Sectors. The data were transcribed verbatim, translated into English,23and then analyzed using an inductive thematic analysis approach.

Results: Three main themes were identified as a result of the qualitative data
analysis: (1) the definition of recovery implies functional recovery, (2) the
definition of recovery implies symptomatic recovery, and (3) the definition of
recovery from a religious perspective.

28 **Conclusions:** The findings of the present study shed light on how recovery in 29 mental health is perceived by service users and their families in the Jordanian 30 context, and they generate insight into what to consider when targeting the 31 development and implementation of recovery-supporting care within the mental 32 health services (MHSs) in Jordan.

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Keywords: recovery, mental illness, service users, family members, Jordan.

# 34 Introduction

The concept of recovery has multiple meanings depending on the context in which it is used (Gandhi et al., 2020). This concept may generate confusion in terms of its understanding by mental health stakeholders, such as Mental Health Professionals

38 (MHPs), service users and their families (Noiseux et al., 2010). However, mental health 39 studies indicate that there are two definitions of recovery from mental illness, based on 40 the models used to define such a concept (Slade et al., 2012; Slade and Longden, 2015; 41 Topor et al., 2018). The first definition is based on the biological model of care, and it is 42 known as clinical recovery (Ostrow and Adams, 2012). This type of recovery stems 43 mainly from professional-led research and practice (Le Boutillier et al., 2015), and it has 44 a shared meaning among all professionals in the mental health field (Slade and Longden, 45 2015).

Clinical recovery is considered by MHPs a result or status that places great 46 emphasis on the use of medical interventions (Slade, 2010) to control or alleviative 47 48 symptoms, improve or restore social and occupational function (Rossi et al., 2018), and 49 to prevent relapse and hospitalization (Donnelly et al., 2011). Accordingly, clinical 50 recovery is commonly conceptualized as an outcome that involves a remission or 51 cessation of mental illness symptoms and a return to a former level of functioning (Slade 52 et al., 2008), that is, a return to 'normal' life before the onset of illness (Lim et al., 2017). Within this conceptualization, clinical recovery can be defined in clinical terminology as 53 54 "it is objective, not subjective", and it can be measured by various objective indicators 55 (Slade and Longden, 2015) such as improved clinical status of service users (i.e. absence 56 or alleviation of symptoms), increased social and vocational functioning (Ng et al., 2011), 57 cessation or reduced use of medication (Nurjannah et al., 2019), and an absence of relapse 58 in psychiatric symptoms (Le Boutillier et al., 2015).

The second definition of recovery is based on the mental health literacy of the service users themselves, and it is termed 'personal recovery' (Bejerholm and Roe, 2018; Van Weeghel et al., 2019). This type of recovery is quite different from clinical recovery, with different definitions, features and outcome indicators. Personal recovery is widely

63 conceptualised as a highly individualised process that is built around service users' unique 64 values, preferences and experiences (Walls et al., 2013). This implies that the concept has a different meaning for each service user and, as such, it may be difficult to standardize, 65 66 reproduce or discover a shared meaning of this concept among service users (Slade and Longden, 2015). In addition, personal recovery is considered to be a continuing process 67 68 that does not involve a cure of symptoms but involves the development of new goals and meaningful, hopeful and productive life by service users, regardless of the limitations 69 70 caused by their mental illness and its impacts (Bejerholma and Roe, 2019). Personal 71 recovery is not an easy or straightforward process, rather it is a non-linear process of growth and healing and may be interspersed with occasional relapses (Leamy et al., 72 73 2011). Furthermore, this process does not necessarily begin from the point of seeking 74 treatment; but it starts with hope, optimism and a belief that service users can recover and 75 overcome any obstacles that they encounter on their road to recovery (Sunderland and 76 Wendy, 2013).

Personal recovery also helps service users take charge of their own health and well-being (Substance Abuse and Mental Health Services Administration (SAMHSA), 2012). It assists them build their strengths, coping skills, and sense of responsibility (Leamy et al., 2011; Thompson, 2014). Accordingly, personal recovery is characterised as an empowering, self-directed, and strengths-based approach (Sheedy and Whitter, 2013).

Personal recovery is also seen as a multidimensional holistic process that involves the different aspects of the life of the service user, including mind, body, spirit and community (Sheedy and Whitter, 2013). This process involves managing the illness, living a healthy physical and emotional life (Storm and Edwards, 2012), developing positive self-identity (Leamy et al., 2011), overcoming social stigma and discrimination (Bromley et al., 2013), developing meaningful social relationships (Tan et al., 2017), and
continuing purposeful participation in community activities (Tse et al., 2014). Thus, the
notion of personal recovery adopts a comprehensive approach to wellbeing that focuses
on service users' strengths (Davidson, 2008).

92 The concept of personal recovery has been globally investigated from the 93 perspectives of different mental health stakeholders, including service users and their 94 families (e.g., Farkas, 2007; Noiseux and Ricard 2008; Piat et al., 2009; Eisenstadt et al., 95 2012; Thara, 2012; Tse et al., 2014; Hickey et al., 2017; Law et al., 2020; Ibrahim et al., 96 2022). This is because personal recovery is a unique and individualized journey, shaped 97 by personal experiences, values, and goals (Anthony, 1993). Hence, understanding the 98 perspectives of service users and their families provides a more nuanced and personalized 99 understanding of what recovery means to them. However, there is variation in the 100 meaning of recovery between studies. For example, some of the studies indicated that 101 many people still see recovery through the lens of clinical recovery (e.g., Eisenstadt et 102 al., 2012; Thara, 2012). Other studies indicated that the concept of recovery is 103 conceptualised as a process involving intrinsic, non-linear progress generated by people with mental illness to rebuild or regain a sense of self, and to improve their own health 104 and wellness (e.g., Noiseux and Ricard 2008). Moreover, other studies argued that 105 106 cultural norms such as religion and belief in God can play an important role in the way 107 that people conceptualise and talk about recovery, especially among Arab and Muslim 108 people and Black and Minority Ethnic groups in Western countries (e.g., Brown et al., 109 2008; Armour et al., 2009; Tse et al., 2005; Al-Solaim and Loewenthal, 2011; Eltaiba and 110 Harries, 2015; and Gamieldien et al., 2021).

The principles of personal recovery became a guiding policy of mental health systems inmany Western countries (Farkas, 2007). Within this policy, MHSs focus on enhancing

113 the strength of service users, self-transformation towards wellness, and providing hope, 114 empowerment, autonomy, social inclusion and self-management (Department of Health 115 and Human Services, 2011; Frost, Heinz and Bach, 2011; Gale and Marshall-Lucette, 116 2012; Piat and Lal, 2012). This policy aims to deliver mental health services that can help 117 users to construct and promote a meaningful life in their communities, regardless of the 118 limitations caused by their illness (Shepherd, Boardman and Slade, 2008). This optimistic 119 view supports the idea of moving away from just the clinical meaning of recovery, which 120 focuses on symptom management, towards a person-centred approach. This approach 121 involves reawakening hope for the future, developing a sense of meaning and purpose in 122 life (Hummelvoll, Karlsson and Borg, 2015), recognizing the unique needs, preferences, and values of service users (Kuipers et al., 2019), and emphasising on collaboration, 123 124 shared decision-making, and a holistic understanding of the individual's well-being 125 (Recto et al., 2023).

A growing body of research supports the efficacy of the person-centred approach 126 127 in promoting mental health recovery and enhancing the quality of MHSs. For example, it was found that this approach can contribute to the improvements of clinical outcomes of 128 129 service users (Cooper et al., 2013), their self-efficacy, empowerment (Fors et al., 2016), 130 treatment engagement, self-management, as well as their overall satisfaction with care 131 (Rathert et al., 2013). Additionally, it is believed that this approach can reduce reliance 132 on inpatient care, health care cost (Bertakis and Azari, 2011), and provide more effective 133 care physically, spiritually and emotionally (Puchalski et al., 2014).

There are still many other non-Western countries, including Jordan, which are trying to incorporate the principles of personal recovery within their mental health system (Jordan Ministry of Health (JMOH), 2011). In particular, Jordanian policy emphasises that there is a need to transform the current MHSs, which rely on the traditional medical 138 model of care, towards recovery-oriented services, and to improve the quality of current

139 MHSs in terms of recovery-supporting care (JMOH, 2011; Hijiawi et al., 2013)

140 The quality improvement process of Jordanian MHSs involves the development, 141 implementation, and adaptation of new standards of care and practice that reflect the ethos 142 of the bio-psychosocial and recovery models, which are considered the main models of 143 care that will guide the Jordanian MHSs in the future (JMOH, 2011). The ultimate 144 purpose of this improvement process is to support the recovery of people with mental 145 illness by providing them with a multidisciplinary, culturally appropriate and integrated 146 mental health care programme that emphasises the protection of their human rights, and 147 guarantees their participation and that of other key stakeholders (e.g. their family 148 members) in their mental health care (JMOH, 2011).

149 Realizing this improvement process necessitates further research on the 150 conceptualization of recovery in Jordan. The dearth of prior research on recovery 151 concepts has resulted in insufficient and limited information for service improvement 152 efforts in Jordan. Therefore, this study aimed to explore the meanings and understandings 153 of recovery in mental health from the perspectives of service users and family members 154 in, Jordan – using findings from a recent qualitative research study - in an attempt to 155 enhance the development and implementation of recovery-supporting care within the 156 MHSs in Jordan.

# 157 Methods and Materials

A qualitative descriptive-phenomenology research design was used in this study to explore the perspectives of Jordanian service users and their families on the meaning of recovery. This design allows researchers to gain an in-depth understanding of a problem under investigation (Lernevall et al., 2020). Ethical approval was gained from the Health and Social Care Ethics Sub-Committee of Middlesex University, London 163 (MH50), as well as from the research ethics committee in the government (MOH-REC-164 160115), military (HREC-19/9/2016) and university (18-98-2016 and 10-2016-5061) 165 health sectors in Jordan. To facilitate the analysis of a manageable volume of qualitative 166 data while ensuring the adequacy of the sample, the sample size of this study was 167 determined based on the concept of information power, as advocated by Malterud et al. 168 (2016)." Accordingly, 16 service users and 16 family members were selected to 169 participate in this study. The participants were selected from 8 acute inpatient mental 170 health units operated by the government, military and university health sectors in Jordan, 171 to capture a wider range of experiences and perspectives. The participants were recruited 172 by conducting many visits to the targeted units during the official visiting hours to reach 173 both service users and their family members at the same time.

174 After briefing the participants and obtaining their written consent to participate in 175 the study, the eligibility for participation was assessed using the eligibility criteria (Table 176 1). Each eligible participant was invited to attend a one-to-one interview conducted in a 177 private place in the selected sectors. Moreover, all interviews with service users were 178 separately conducted to prevent any influence from the service users on their family 179 opinions and to ensure the consistency of the interview. The data were collected over 3 180 months from March 2017 to May 2017 by using a semi-structured interview guide 181 developed by the researchers, (for detailed interview guide, see Supplementary 182 Materials). Semi-structured interviews are an efficient technique to get in-depth 183 information about perspectives and experiences of people in interpretive research. Hence, 184 they allow researchers to ask specific questions while also giving participants the freedom 185 to share their own stories (Balushi, 2016).

186 All the interview responses were recorded using a digital recorder and saved on a187 password-protected computer. The collected data were transcribed verbatim in Arabic

and translated into English. Then, all transcripts were back-translated to Arabic by a
bilingual expert to ensure the translation validity and avoid any translation-related
problems (Birbili, 2000).

191 The data were analyzed using both inductive and deductive thematic analysis 192 techniques proposed by Braun and Clarke (2006). Firstly, the interview transcripts were 193 explored to gain an in-depth understanding of the data set as a whole. This was achieved 194 by reading through both the Arabic and English transcripts several times and listening to 195 the audio recordings when necessary (Maguire and Delahunt, 2017). Prior to starting the 196 actual data analysis process, a deductive analysis approach was employed by creating a group of open nodes on the NVivo software (Version 11) that represented the topics 197 discussed during the interviews. This included the meaning of recovery and the 198 199 characteristics/indicators of recovery. After this, the analysis process of textual data was 200 started by using an inductive analysis approach to make connections between nodes and 201 to code data segments of interest in creating themes and related sub-themes. The coding 202 process continued, reviewing and refining the coded data in an iterative process by all 203 author to ensure that the themes/sub-themes created were empirically and conceptually 204 meaningful. The generated themes were each given a suitable name reflecting the essence 205 and aspects captured by each theme. In total, three main themes and related sub-themes 206 on the meanings and understandings of recovery in mental health emerged from the 207 qualitative data.

208 **Results** 

# 209 The Study participants

A total of 16 service users and 16 family members participated in the study.
Service users ranged in age between 18-57 years and family members between 28-65.
Half of the participants (n=16) (including service users and their family members) were

recruited from the government sector, and most of them had completed diplomas or
university-level education. The sociodemographic characteristics of participants are
presented in Table (2).

216 The Conceptuality of Recovery

The analysis revealed three key themes emerging from the data: 1) the definition of recovery implies functional recovery, 2) the definition of recovery implies symptomatic recovery, and 3) the definition of recovery from a religious perspective. These themes are explained and discussed in the following sections.

221 Definition of recovery implies functional recovery

222 Half of service users and family members tended to agree that the definition of 223 recovery from mental illness implied a status that was more than symptomatic remission. 224 This status involved a complete restoration of the previous level of function and 225 independence that the service users had before the onset of mental illness "getting back 226 to normal". There were, however, three key varying perspectives among the participants 227 in terms of the indicators associated with this status. Firstly, eight service users and family 228 members viewed regaining of the previous functionality situation and social relationships 229 to be indications of recovery. For example:

Recovery means that I'll get back to my old life as a normal person who carries out his work normally and interact with relatives and community without any barriers and fears... [SU13] Secondly, three family members and two service users viewed that regaining independence and achieving meaningful goals would also be an indication of recovery. This dimension of recovery encompassed different life aspects, including education and employment. For example:

- The recovery of my daughter means that she'll be a normal person again; she'll be able to feel that she is an independent person again. She'll be able to carry out all her tasks to the fullest, get back to her school, and achieve her dream of joining the university [FM11]
- Recovery means that I'm a self-independent person again who can work and earn
  money...Once I get a job, I'll consider my recovery has happened. [SU4]

241 Finally, two family members and one service user expressed that having a stable family

and raising children in a calm environment would also be an indicator of recovery. As

this interviewee, for example, commented:

Recovery means that my husband will be the normal person he was before... He will get back to caring about the kids and me, and he will try his best to offer us a good life full of love and kindness. [FM6]

Based on the above, the definition of recovery provided by the participants went beyond a status of symptomatic remission to include a real regaining of a suitable range of normal day-to-day functions. The study participants looked at the recovery process not through the lens of personal recovery, but rather as a clinical recovery that focuses on restoring the normal level of function.

252 Definition of recovery implies symptomatic recovery

There was general harmony amongst four service users and three family members 253 254 that the definition of recovery implied symptomatic recovery. This concept was defined 255 by two service users and two family members as a complete cure (absence) of the 256 symptoms, whereas other participants referred to it as the state of being completely healed 257 or cured from the illness. The aforementioned participants had, however, different views 258 to explain the concept of symptomatic recovery in terms of indicators or conditions 259 associated with this concept. For instance, two service users believed that the absence of 260 relapse in psychiatric symptoms is an essential indicator of recovery. However, other 261 participants (two service users and three family members) still believed that the complete

262 cessation of medication would be a clearer indicator of recovery. Therefore, these 263 participants defined recovery as a situation that involved not only a complete cure of the 264 symptoms of mental illness but also one associated with a situation of complete cessation 265 of taking medication. One service user, for example, stated:

Recovery means that I am cured of this illness...This means that I'll not talk or think too
much, I'll sleep very well...Most importantly, I'll not take medications anymore... [SU10]

This perspective suggests that recovery was considered as an outcome of a medical process that involves curing the signs and symptoms of illness and can be determined by the complete cessation of medication. This view was also held by the family members, as the following interviewee stated:

Recovery means that the thoughts, delusions and obsessions that my son has in his mind,
will vanish, and he will not need to take the medication or visit doctor anymore. [FM14]

274 In this study, there was a debate among some of the participants regarding the degree of 275 recovery in symptoms. Four participants argued that the symptoms of mental illness were 276 incurable, chronic and persistent, and it was very difficult for them or their loved ones to 277 reach a status involving a complete cure of the symptoms or illness. Thus, they considered 278 recovery as a status that involved controlling/stabilising the symptoms of mental illness, 279 rather than a complete cure of the symptoms. As a result, the participants considered 280 adherence to medication as an essential condition to reach this status, as indicated by the 281 following two comments:

there is no full recovery from mental illness; it is chronic and lasts with the patient forever... I think recovery occurs when the symptoms of illness come under control and the severity of the illness decrease. Unfortunately, this can't be achieved without taking medications. [FM3] 286

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Recovery means to me that my health situation stays stable by keep taking the medication on a regular basis all my life. [SU2]

From these perspectives, the participants of service users and their family members seemed to perceive recovery as an outcome of a medical process involving curing or at least controlling the symptoms of mental illness, and this perspective in turn strongly aligned with the features of clinical recovery rather than the features and characteristics of personal recovery.

# 293 Definition of recovery from a religious perspective

294 Although many participants believed that adherence to medications was the main 295 way to achieve recovery, other participants (two service users and three family members) 296 did not express this view. These participants, in particular, talked about recovery within 297 the context of their spiritual/religious beliefs. They believed that the reasons behind the 298 occurrence of mental illness and recovery were due to the will of Allah (God). Although 299 these participants viewed recovery as a situation where the mental illness was completely 300 cured, they strongly emphasised that this situation could only be achieved by the will of 301 Allah. For example:

Although medications may help control my symptoms, I still see that my full recovery
will surely happen if Allah allows... I know that everything in this life is in the hands of Allah,
he is the only one who can make me sick or help me to recover. [SU7]

305 Thus, religion and other spiritual beliefs appeared significant to some of our participants 306 in how they perceived both mental illness and the recovery process.

# 307 Discussion

308 The findings of this study indicated that most Jordanian service users and their 309 family members had a traditional medical perspective on the concept of recovery from 310 mental illness. They viewed recovery primarily as a clinical outcome of a medical 311 process. They considered that the definition of recovery implied three main concepts: 312 symptomatic recovery, functional recovery, and recovery from a religious perspective. 313 Whilst the first concept referred to a situation of symptom remission (either the reduction 314 or disappearance of the symptoms of mental illness), the second one involved service 315 users regaining the level of function and independence that they had before the onset of 316 their mental illness, and the third one referred to a situation that involves a remission of 317 symptoms, only achieved by the Will of Allah.

Service users and their family members also considered that cessation of medications, the absence of any relapse in psychiatric symptoms, and the restoration of previous social and vocational functioning were important indicators of recovery. This reflects their perception that recovery from mental illness was similar to that of physical illness, that is, the sense of remission of symptoms and return to a pre-morbid level of functioning (Mueser et al., 2006).

324 The findings of this study are consistent with other qualitative studies from non-325 Western countries. Two separate studies, conducted in Brazil (Eisenstadt et al., 2012) and 326 India (Thara, 2012), showed that the vast majority of service user participants considered 327 recovery as being a decrease or absence of symptoms, the regaining of functional 328 autonomy, a return to social life, and the absence of relapses and cessation of medications. 329 These findings indicate that people with mental illness in such countries tend to view 330 recovery from mental illness as the outcome of a process that is routinely medical rather 331 than as a highly personalised process.

The findings are also consistent with the results of previous international and local studies conducted by Tse et al. (2005); Brown et al. (2008); Armour et al. (2009); Al-Solaim, and Loewenthal (2011); Eltaiba and Harries (2015); and Gamieldien et al. (2021), in which all reported that their participants talked about their recovery experiences within
the context of their religion; a belief in God as a higher power in facilitating and achieving
recovery. As observed in the current study, it is concluded that such beliefs play a central
role in the way that Jordanian service users perceived their recovery from mental illness
(Eltaiba and Harries, 2015).

340 The findings of this study, however, were inconsistent with those from studies 341 conducted in Western countries. For example, A Canadian qualitative study conducted 342 by Noiseux and Ricard (2008) to introduce an explanation of recovery from schizophrenia 343 from the perspectives of service users, family members and mental health professionals produced findings indicating that the study participants viewed recovery as a process 344 involving seven main steps. These included: experiencing illness, igniting a spark of 345 346 hope, developing insight, activating the instinct to fight back, discovering keys to well-347 being, maintaining a constant equilibrium between internal and external forces, and 348 seeing the light at the end of the tunnel. The results revealed that in the Western countries 349 where a recovery model has acquired more acceptance and proved more useful in mental 350 health services than a biological model, recovery from mental illness is conceptualised as 351 a process involving intrinsic, non-linear progress generated by people with mental illness 352 to rebuild or regain a sense of self and maintain a balance between internal and external forces to navigate the social world, regain a sense of well-being across all biopsychosocial 353 354 levels(Noiseux and Ricard 2008), and to develop a meaningful, hopeful and productive 355 life in a community of their choice (Bejerholm and Roe, 2018).

To the best of our knowledge, no potential biases were identified in the study. However, this study has several limitations. Since the data were collected from 16 service users and 16 family members, it is unclear how representative the sample is of other Jordanian service users and their family members. Another limitation is the 360 generalisability of the study findings - some of the data were collected from the 361 government, military and university sectors in Jordan and, hence, it is difficult to 362 generalise the findings to other sectors, such as the private sector. Despite these 363 limitations, this research was the first study to explore the meaning of recovery in Jordan 364 form the perspectives of service users and their families.

365 **Conclusion and implications** 

366 This study delved into the concept of recovery among Jordanian service users and their 367 families, revealing three core dimensions: symptomatic recovery, functional recovery, 368 and recovery from a religious perspective. The findings additionally identified factors that 369 facilitate recovery, such as medication adherence and a strong faith in God. Furthermore, 370 the study outlined several indicators of recovery, including cessation of medication, 371 absence of psychiatric symptom relapse, and the restoration of previous social and 372 vocational functioning. The findings of this study suggests that MHSs in Jordan should 373 prioritize initiatives that enhance support for the recovery of individuals with mental 374 illness. These initiatives may include implementing comprehensive treatment plans 375 grounded in evidence-based practices, such as psychotherapy and medication 376 management, to effectively manage psychiatric symptoms and promote overall well-377 being, adopting personalized well-being and recovery planning tools, such as the 378 Wellness Recovery Action Plan (Copeland, 2002), to assist service users in adhering to 379 medication, maintaining symptom control, and preventing relapse, providing regular 380 psychoeducation sessions for service users to foster a comprehensive understanding of 381 their illness and treatment options, encouraging and facilitating opportunities for service 382 users to engage in meaningful social interactions, pursue employment, and continue their 383 education, designing and implementing interventions that focus on helping service users 384 regain independence, improve their quality of life, and fully participate in their 385 communities, acknowledging and respecting the role of religious beliefs in shaping 386 individuals' perceptions of mental health and recovery, providing opportunities for 387 service users to integrate their religious beliefs into their recovery journey, fostering a 388 sense of hope, meaning, and spiritual well-being, recognizing the unique cultural and 389 social factors that influence the experiences of individuals with mental health conditions 390 in Jordan, and adapting MHSs to align with the specific needs and preferences of 391 Jordanian service users and their families.

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## **396 Disclosure statement of interest**

397 The authors declare that they do not have any conflicts of interest.

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