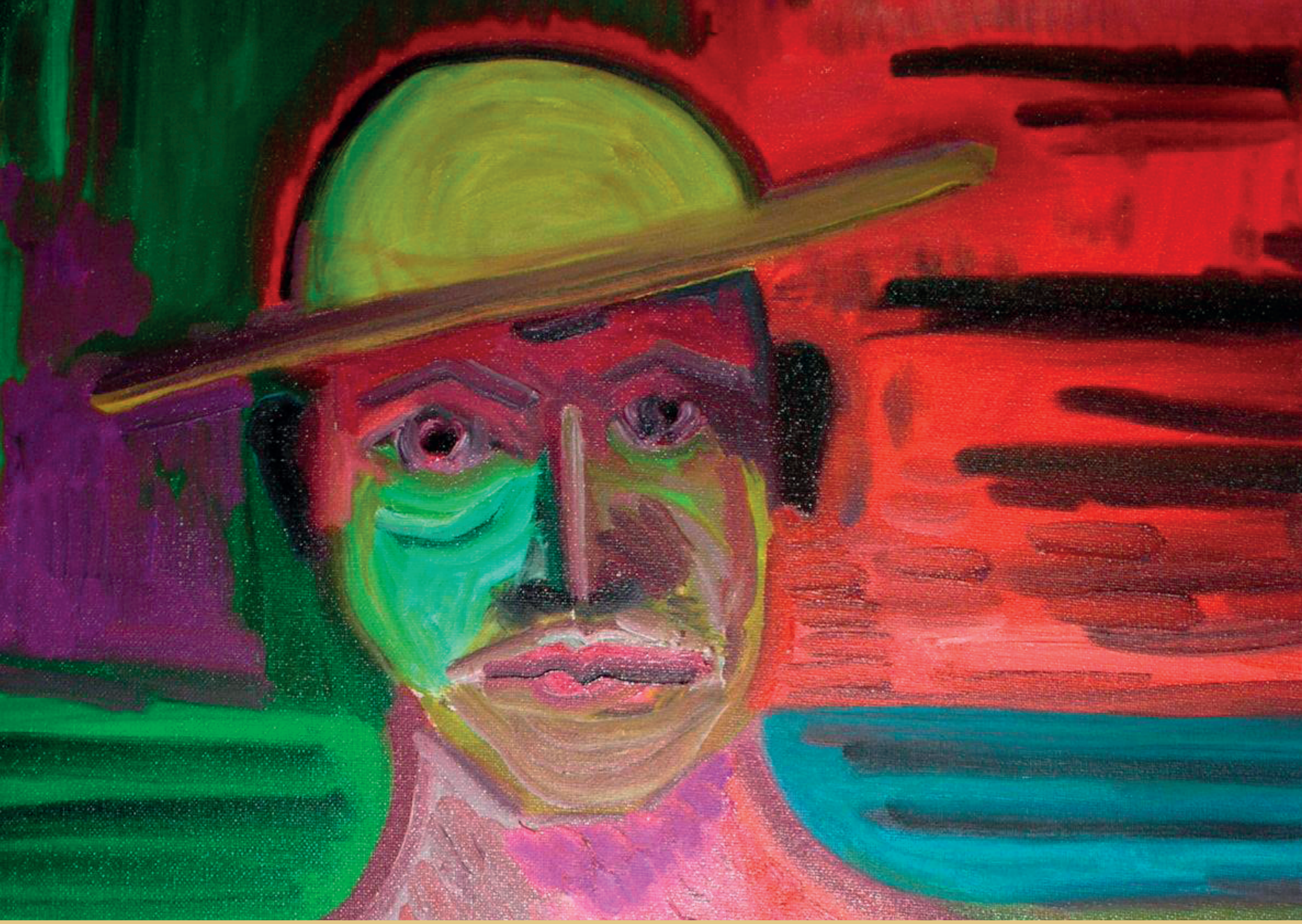

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CONTRIBUTOS PARA O DESENVOLVIMENTO DE SERVIÇOS DE REABILITAÇÃO PSICOSSOCIAL/PSIQUIÁTRICA EM PORTUGAL:

SITUAÇÃO ATUAL, BARREIRAS E DESAFIOS

Tese de Doutoramento em Psicologia (especialidade de Aconselhamento) orientada pelo Professor Eduardo Santos e pelo Professor Julian Leff apresentada à Faculdade de Psicologia e de Ciências da Educação da Universidade de Coimbra

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Contributos para o Desenvolvimento de Serviços de Reabilitação Psicossocial/Psiquiátrica em Portugal:

Situação atual, barreiras e desafios

Contributions to the Development of Psychosocial/Psychiatric Rehabilitation Services in Portugal:

Current status, barriers and challenges

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POPH
PROGRAMA OPERACIONAL POTENCIAL HUMANO

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QUADRO DE REFERÊNCIA ESTRATÉGICO NACIONAL
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“It must be borne in mind that the tragedy of life doesn’t lie in not reaching your goal. The tragedy lies in having no goal to reach. It isn’t a calamity to die with dreams unfulfilled, but it is a calamity not to dream. It is not a disaster to be unable to capture your ideal, but it is a disaster to have no ideal to capture. It is not a disgrace not to reach the stars, but it is a disgrace to have no stars to reach for. Not failure, but low aim is sin.”

Benjamin Elijah Mays

Resumo

A reabilitação psiquiátrica/psicossocial é a área do sistema de saúde mental que visa melhorar o funcionamento das pessoas com doença mental em determinados papéis da sua escolha no "mundo real". A Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental desenvolveu um Plano de Ação com vista à reforma do sistema de saúde mental português entre 2007 e 2016, prevendo, entre outras medidas, a implementação de programas de reabilitação psiquiátrica.

Seis anos após a publicação do Plano de Ação supramencionado revela-se da máxima importância avaliar a execução prática das recomendações nele contidas. Assim, os principais objetivos desta tese são: 1) analisar a situação atual da reabilitação psiquiátrica em Portugal e as barreiras ao seu desenvolvimento; 2) com base na análise efetuada, formular recomendações para a melhoria dos serviços de reabilitação psicossocial no nosso país.

O primeiro capítulo desta tese elucida-nos sobre os programas de reabilitação psicossocial atualmente existentes em Portugal. Foi enviado um inquérito a 70 instituições de todo o país, questionando-as sobre a prestação de diferentes programas de reabilitação psiquiátrica. O nosso objetivo foi avaliar até que ponto programas baseados em evidência e práticas promissoras estão implementados no nosso país. Concluímos que o único programa recomendado pelas orientações internacionais que está razoavelmente implementado no nosso país é a psicoeducação multi-familiar. O emprego apoiado, a educação apoiada e a habitação apoiada estão ainda insuficientemente disseminados.

Tendo em conta que a avaliação dos programas de reabilitação psiquiátrica não é feita, por rotina, no nosso país, levamos a cabo um estudo transversal, que é descrito no

capítulo 2, com o objetivo de explorar diferenças no funcionamento global, social e ocupacional, qualidade de vida e auto-conceito entre três grupos de pessoas com perturbações do espectro da esquizofrenia: formação profissional, atividades ocupacionais, e um grupo de controlo de utentes desempregados que não estavam a participar em qualquer tipo de programa de reabilitação psicossocial. Os indivíduos em formação mostraram níveis mais elevados de funcionamento social e ocupacional do que os indivíduos em atividades ocupacionais, embora não tenham sido encontradas diferenças significativas entre as pessoas em formação e as pessoas sem qualquer atividade, nem entre o grupo em atividades ocupacionais e o grupo que não frequentava qualquer programa. Não foram detetadas diferenças na qualidade de vida entre os três grupos.

Assim, apesar de 92.9% das instituições portugueses avaliadas no estudo descrito no capítulo 1 prestarem atividades ocupacionais, o estudo descrito no capítulo 2 falhou em mostrar diferenças em termos de qualidade de vida e de funcionamento global, social e ocupacional entre pessoas com doença mental que participavam nestas atividades e pessoas com doença mental que não frequentavam qualquer programa de reabilitação. O estudo descrito no capítulo 1 mostrou ainda que a grande maioria dos programas de reabilitação nas áreas da educação e emprego é constituída por cursos de formação profissional específicos para pessoas com incapacidades. No entanto, a investigação descrita no capítulo 2 não mostrou diferenças significativas em termos de funcionamento social e ocupacional e de qualidade de vida entre os indivíduos em formação e os indivíduos sem qualquer atividade.

No terceiro capítulo, descrevemos uma instituição de reabilitação psiquiátrica portuguesa e analisamos barreiras à mudança de paradigma. Estas barreiras (verificadas também nos estudos descritos nos capítulos iniciais) incluem a prestação de intervenções sem efetividade comprovada, um défice de avaliação da qualidade dos serviços, a falha dos profissionais em se manterem atualizados, bem como as suas atitudes negativas em relação aos utilizadores dos serviços.

Por sua vez, o capítulo 4 é constituído por uma revisão narrativa da literatura sobre o estigma da doença mental. A análise mostrou que as famílias e os profissionais são ao mesmo tempo perpetradores e vítimas de estigma, de modo que é urgente combater as diferentes facetas em que o estigma se expressa. De salientar, que as atitudes de muitos profissionais não diferem das atitudes da população em geral, sendo, por vezes, mais negativas.

Em suma, os diferentes capítulos que compõem esta tese dão-nos informações importantes sobre o *status quo* da reabilitação psicossocial em Portugal. Verificamos que os serviços de reabilitação portugueses são maioritariamente caracterizados por contextos educacionais segregados e unidades habitacionais, da propriedade dos serviços, para a vida em grupo de pessoas com doença mental. Estes modelos são obsoletos e a literatura mostra claramente que não favorecem a integração comunitária e a recuperação das pessoas com doença mental. Os contextos segregados opõem o princípio da recuperação, o qual, ao invés de restringir as pessoas com doença mental a guetos, implica promover papéis valorizados fora dos contextos dos serviços de saúde mental.

A luta contra estigma é um dos fatores mais importantes para o alcance da integração comunitária das pessoas com doença mental. Esta luta deve começar nos próprios profissionais, que subestimam as capacidades das pessoas com doença mental, acabando por lhes transmitir mensagens de desesperança, que afetam a sua luta pela recuperação e pelo alcance de objetivos pessoais.

Assim, é urgente implementar programas baseados em evidência e assegurar que estes sejam previstos na legislação; promover uma abordagem de reabilitação baseada no paradigma da recuperação; proporcionar formação aos profissionais; criar programas de redução de estigma; e promover uma cultura de avaliação de serviços.

Abstract

Psychiatric/psychosocial rehabilitation is the field within a mental health system which aims to improve the functioning of people with mental illness in specific roles of their choice in the "real world". The National Commission for the Restructuring of Mental Health Services has developed an Action Plan to reform the Portuguese mental health system between 2007 and 2016, foreseeing, among other measures, the implementation of psychiatric rehabilitation programmes.

Six years since the publication of the abovementioned Action Plan, it is of utmost importance to assess the practical execution of its recommendations. Therefore, the main aims of this thesis are: 1) to analyse the current status of psychiatric rehabilitation in Portugal and the barriers to its development; 2) based on this analysis, to formulate recommendations for the improvement of psychosocial rehabilitation services in our country.

The first chapter of this thesis reports on the current existent psychosocial rehabilitation programmes in Portugal. A survey was sent to 70 institutions throughout Portugal asking if they provided different types of psychiatric rehabilitation programmes. We aimed to evaluate to what extent evidence-based programmes and promising practices are implemented in our country. We concluded that the only programme recommended by the international guidelines which is reasonably implemented in our country is multi-family psychoeducation. Supported employment, supported education and supported housing are still poorly disseminated.

Taking into account that the evaluation of psychiatric rehabilitation programmes is not routinely done in our country, we carried out a cross-sectional study, which is described in chapter 2, to explore differences in the global, social and occupational functioning, quality of life and self-concept between three groups of persons with schizophrenia spectrum disorders: vocational training, occupational activities, and a control group of unemployed users who were not attending any type of psychosocial intervention. Individuals in training showed higher scores in social and occupational functioning than those in occupational activities, although no significant differences were found neither between training participants and individuals with no activity, nor between the occupational activities group and the group not attending any programme. Differences in quality of life were not detected between the three groups.

Thus, although 92.9% of the portuguese institutions evaluated in the study described in chapter 1 provide occupational activities, the study described in the second chapter failed to show differences in quality of life and in global, social and occupational functioning between people with mental illness who participated in these activities and people with mental illness who were not attending any rehabilitation programme. The national survey also showed that the vast majority of rehabilitation programmes in the areas of education and work consists of vocational training specific for people with disabilities. However, the investigation described in Chapter 2 did not show significant differences in terms of social and occupational functioning and quality of life between individuals in training and individuals with no rehabilitation activity.

In Chapter 3, we describe a portuguese psychiatric rehabilitation institution and analyse barriers to the paradigm shift. These barriers (also observed in the studies described in the previous chapters) include the provision of interventions whose effectiveness is not demonstrated, a lack of evaluation of services quality, the failure of professionals to keep up to date, as well as their negative attitudes towards the persons that utilise the services.

In turn, the fourth chapter consists of a literature review on stigma of mental illness. The analysis showed that families and professionals are both perpetrators and victims of stigma, so that it is urgent to combat the different facets in which stigma is expressed. It is noteworthy that the attitudes of many professionals do not differ from the attitudes of the general population, and sometimes are even more negative.

In short, the different chapters which compose this thesis give us important information on the *status quo* of psychosocial rehabilitation in Portugal. We verified that psychosocial rehabilitation in Portugal is characterised by the provision of training courses in segregated educational contexts and by services-owned residential units for the group living of people with mental illness. These models are obsolete and the literature clearly shows that they do not promote community integration and recovery. The segregated settings oppose the principle of recovery, which, instead of restricting people with mental illness to ghettos, implies promoting valued roles outside the context of mental health services.

Combating stigma is one of the most important factors for the achievement of community integration of people with mental illness. This fight should start in the professionals themselves, who underestimate the capacities of people with mental illness and convey messages of hopelessness that affect their struggle for recovery and for the attainment of personal goals.

Thus, it is urgent to implement evidence-based programmes and to ensure that they are provided for by legislation; to promote a rehabilitation approach based on the recovery paradigm; to provide professionals with training; to create programmes to reduce stigma; and to promote a culture of services evaluation.

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Às pessoas com experiência vivida de doença mental e às instituições de saúde mental que colaboraram nos diversos estudos que compõem esta tese, o meu profundo obrigado. Juntos lutaremos para que serviços que respeitem a liberdade e a dignidade humana da pessoa com doença mental sejam implementados.

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Introdução[1]

A Reabilitação Psicossocial no contexto da prática terapêutica das doenças mentais: aparecimento, fundamentação, modalidades

A reabilitação psicossocial é um processo que oferece a oportunidade às pessoas que estão em situação de incapacidade ou desvantagem devido a uma doença mental de alcançarem o seu nível ótimo de funcionamento autónomo na comunidade. Envolve tanto a melhoria de competências individuais, como a introdução de alterações ambientais. A reabilitação psicossocial é um processo abrangente e não apenas uma técnica (Organização Mundial de Saúde, OMS, 2001).

King, Lloyd, Meehan, Deane e Kavanagh (2012) oferecem uma definição mais lata referindo que a reabilitação psicossocial é um conjunto de intervenções não farmacológicas que têm como objetivo ajudar pessoas com doença mental severa no seu processo de recuperação (*recovery*).

Anthony, Cohen, Farkas e Gagne (2002) utilizam o termo reabilitação psiquiátrica, enfatizando, desta forma, a população que é o foco da reabilitação, isto é, as pessoas com incapacidade psiquiátrica. As últimas definem-se por terem uma doença mental diagnosticada que limita a sua capacidade para desempenhar determinadas tarefas e funções (e.g., interagir com a família e amigos, fazer uma entrevista de emprego) e a sua capacidade para desempenhar determinados papéis (e.g., trabalhador, estudante). Neste sentido, a reabilitação psiquiátrica é o campo dentro do sistema de

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[1] A Introdução desta tese será publicada, com as devidas alterações, no livro *Jovens Adultos*, editado pelo Professor Castro Fonseca.

saúde mental que visa melhorar o funcionamento das pessoas com doença mental em determinados papéis da sua escolha (e.g., estudante) no “mundo real”, utilizando para tal o desenvolvimento de competências e suportes como intervenções primárias (Anthony et al., 2002; Farkas & Anthony, 2010).

Aparecimento

Apesar de ideias consistentes com a abordagem da reabilitação psiquiátrica terem surgido na era da terapia moral no século XIX, na qual se enfatizava a avaliação global da pessoa com incapacidade psiquiátrica (examinando atividades sociais, laborais e de lazer), a aceitação geral da reabilitação psiquiátrica como um campo credível e legítimo ocorreu apenas nos anos 80 do século passado (Anthony et al., 2002).

Na América do Norte e na Europa, a segunda metade do século XX é caracterizada pelo movimento de desinstitucionalização (Alves & Silva, 2004). A década de 80 foi uma época de transição, particularmente na América do Norte, entre a anterior era de desinstitucionalização (que decorreu nas décadas de 1960 e 1970) e a era da reabilitação (Anthony et al., 2002). Como referem Anthony e colaboradores (2002), a desinstitucionalização reduzia-se a um simples objetivo: transferir as pessoas com doença mental para a comunidade. Os autores acrescentam “Deinstitutionalisation opened the doors of the institutions and literally gave people a prescription for their medicine when they left. However, rehabilitation attempts to open the doors of the community and help people figuratively develop a prescription for their lives” (Anthony et al., 2002, pág. 2).

Fundamentação (valores)

A reabilitação psicossocial/psiquiátrica sofreu, nas últimas três décadas, um grande desenvolvimento devido, em grande parte, ao trabalho do *Center for Psychiatric Rehabilitation* da Universidade de Boston. Resumem-se de seguida aspetos essenciais resultantes da vasta investigação desenvolvida na respetiva Instituição e que estão pormenorizadamente descritos na obra de Anthony e colaboradores (2002).

Na sua essência, o objetivo da reabilitação psiquiátrica é melhorar o funcionamento das pessoas e fazer com que elas se sintam mais satisfeitas nos contextos sociais, de aprendizagem e de trabalho da sua escolha. Este objetivo é alcançado através do desenvolvimento quer das competências do indivíduo, quer de suportes no ambiente. A assunção da reabilitação psiquiátrica é a de que através de mudanças positivas nas competências das pessoas e/ou no ambiente, benefícios no desempenho de um papel advirão.

A filosofia da reabilitação psiquiátrica baseia-se num modelo conceptual que descreve as várias dimensões afetadas pela doença mental. De acordo com este modelo, a doença causa prejuízo (sintomas), disfunção (dificuldade para desempenhar tarefas ou atividades), incapacidade (dificuldade para desempenhar um papel) e desvantagem (falta de oportunidades, que limitam ou previnem o desempenho de uma atividade ou de um papel). Assim, os proponentes da reabilitação psiquiátrica enfatizam que a doença mental não só causa sintomas, mas também limitações funcionais, incapacidades e desvantagens.

Enquanto o tratamento tem como objetivo o alívio dos sintomas, a reabilitação promove o desenvolvimento de competências e de apoios, bem como alterações no ambiente, os quais vão de encontro aos objetivos pessoais da pessoa com doença mental, visando melhorar o seu funcionamento e satisfação.

Assim, o diagnóstico psiquiátrico tem pouco para oferecer à abordagem da reabilitação psiquiátrica. Objetivos, competências, interesses, e interações com outros significativos são a quinta-essência da avaliação no âmbito da reabilitação (Anthony et al., 2002). O campo da reabilitação psiquiátrica enfatiza o tratamento das consequências da doença, mais do que a doença *per se* (Anthony, 1993).

Enquanto o tradicional papel "paciente-terapeuta" do tratamento clínico implica expectativas de adesão, o papel "utente-profissional" da reabilitação preconiza a auto-determinação e a capacitação (*empowerment*), ou seja, a atribuição de poder à pessoa com doença mental (Farkas, 1999).

Anthony e colaboradores (2002) identificam 8 valores básicos que guiam o campo da reabilitação: *orientação para a pessoa*, isto é, a reabilitação enfatiza a abordagem do ser humano como um todo, englobando os seus interesses, valores, talentos, expetativas, medos, ao invés do foco na doença ou rótulo diagnóstico; *funcionamento*, ou seja, a reabilitação destina-se a melhorar o funcionamento, mais do que a reduzir sintomas; prestação de *apoio* durante o tempo que for necessário e desejado; *especificidade ambiental*, enfatizando a importância do contexto específico onde a pessoa vive, aprende, socializa e trabalha; *envolvimento*, isto é, inclusão dos indivíduos com doença mental como parceiros em todos os aspetos da reabilitação (a reabilitação é feita *com* as pessoas com doença mental e não *para* as pessoas com doença mental); *escolha*, ou seja, as pessoas com incapacidades psiquiátricas têm direito à cidadania, o que significa ter o direito de escolher como viver a sua vida, onde viver, estudar e trabalhar (as pessoas que estão num programa não são forçadas a integrar qualquer tipo de contexto); *orientação para os resultados*, ou seja, a reabilitação psiquiátrica é orientada para resultados observáveis e não para a simples prestação de serviços (a avaliação de um programa não mede somente a provisão de serviços, por exemplo, o número de horas de serviços prestados). Os resultados em reabilitação são definidos como o nível de sucesso e satisfação dos indivíduos nos contextos da sua escolha); *potencial de crescimento*, o que quer dizer que independentemente das dificuldades atuais da pessoa, o foco é a melhoria do sucesso e da sua satisfação.

A reabilitação psiquiátrica ajudou o campo da saúde mental a compreender que as pessoas com incapacidades psiquiátricas, contrariamente ao mito histórico, podem recuperar. Esta mudança de paradigma em relação à recuperação da doença mental deu origem à visão de *recovery*, que é agora um importante componente da filosofia da reabilitação psiquiátrica (Anthony & Farkas, 1999)

A recuperação (*recovery*) é um processo profundamente pessoal e único de mudança de atitudes, valores, sentimentos, objetivos, competências, e/ou papéis. É uma forma de viver uma vida satisfatória, com esperança e significado, com ou sem as limitações causadas pela doença. A recuperação envolve o desenvolvimento de um novo significado e propósito para a vida enquanto a pessoa cresce além dos efeitos catastróficos da doença mental (Anthony, 1993).

Recuperação não significa necessariamente restaurar o pleno funcionamento sem qualquer tipo de apoio (incluindo medicação); significa trabalhar sobre as forças pessoais e recursos para desenvolver mecanismos de *coping* que capacitam os indivíduos a tornarem-se participantes ativos, e não simples beneficiários passivos, nos seus cuidados de saúde mental (Allot, Loganathan, & Fulford, 2002). Recuperação significa assumir o controlo/comando da própria vida, mesmo que não se possa assumir o controlo/comando completo dos sintomas (Anthony & Farkas, 1999).

Leamy, Bird, Le Boutillier, Williams and Slade (2011) desenvolveram um modelo conceptual de recuperação onde identificam os processos que o constituem. Os processos de recuperação podem ser entendidos como dimensões mensuráveis de mudança, que tipicamente ocorrem durante a recuperação, e fornecem uma taxonomia dos seus resultados esperados. Estes processos são conexão (e.g., suporte, ser parte de uma comunidade); esperança e otimismo em relação ao futuro (e.g., ter sonhos e aspirações), identidade (e.g., redefinir o sentido de identidade, ultrapassar o estigma), ter um sentido para a vida; e responsabilidade pessoal/controlo sobre a própria vida (*empowerment*).

A recuperação transcende a doença e o campo das incapacidades. De acordo com Anthony (1993), a recuperação é uma experiência humana verdadeiramente unificadora. Todas as pessoas experienciam catástrofes na vida (e.g., morte de um ente querido, divórcio, doença física severa) e, portanto, todos, em algum momento da vida, enfrentamos o desafio da recuperação. A recuperação de uma catástrofe não muda o facto de que a mesma ocorreu, que os seus efeitos estão ainda presentes e que a vida mudou para sempre. A recuperação com sucesso significa que a pessoa mudou e que, por isso, o significado dos factos para a pessoa mudou. Esses factos não são mais o foco primário da existência, pois segue-se em frente, procurando outros interesses e atividades (Anthony, 1993) e redefinindo objetivos.

Modalidades

O *Center for Psychiatric Rehabilitation* da Universidade de Boston desenvolveu uma abordagem da reabilitação psiquiátrica, o modelo escolher-obter-manter (*choose-get-keep model*, Anthony et al., 2002), com o objetivo de guiar os profissionais na construção de uma relação com os indivíduos com doenças mentais severas, que facilite a escolha, a obtenção e a manutenção de um papel pessoal e socialmente valorizado (Farkas & Anthony, 2010). As intervenções de reabilitação psicossocial/psiquiátrica enquadram-se neste processo.

Existe um vasto leque de programas para ajudar as pessoas com doença mental a escolher, obter e manter o papel que pretendem desempenhar no futuro. O emprego apoiado é um programa que coloca as pessoas com incapacidades no mercado normal de trabalho. Um modelo específico de emprego apoiado para pessoas com doença mental severa, o programa de colocação e apoio individuais (*individual placement and support*) foi desenvolvido nos anos 90 do século passado por Becker e Drake (Becker & Drake, 1994; Drake & Becker, 1996). O modelo de colocação e apoio individuais é uma abordagem baseada em evidência e caracteriza-se pelos seguintes princípios (Bond, 1998; 2004): serviços focados em emprego competitivo, elegibilidade baseada na escolha da pessoa em reabilitação (ninguém é excluído), procura rápida de emprego, reabilitação integrada na equipa de saúde mental, atenção às preferências da pessoa em reabilitação, apoio individualizado e ilimitado, aconselhamento de benefícios (por exemplo, no que diz respeito a pensões de invalidez).

As empresas sociais constituem outro modelo de reabilitação profissional. Estas consistem em empresas geridas, pelo menos em parte, pelas pessoas com incapacidades, com a missão de criar um produto ou serviço necessário e empregar pessoas em situação de desvantagem (Leff & Warner, 2006; Warner & Mandiberg, 2006). Estas empresas não procuram criar um ambiente artificialmente protegido (OMS, 2001) e oferecem uma grande variedade de postos de trabalho, sendo que pessoas com incapacidade com qualificações escolares/profissionais superiores podem desempenhar cargos administrativos ou, pelo menos, tarefas mais estimulantes (Leff & Trieman, 2000).

Em relação ao suporte na área da educação, destacamos o modelo de educação apoiada desenvolvido no *Center for Psychiatric Rehabilitation* da Universidade de Boston (Anthony & Unger, 1991; Unger, Danley, Kohn, & Hutchinson, 1987). Este programa apoia as pessoas com doença mental severa a aceder a educação em cursos destinados à população geral. Os profissionais apoiam a pessoa em reabilitação em aspetos que aumentam a probabilidade de sucesso no alcance do objetivo educacional, como a escolha do programa, processo de inscrição e possibilidades de ajuda financeira (Unger, Pfaltzgraf, & Nikkel, 2010). Os serviços nucleares podem ser agrupados em planeamento da carreira, competências académicas e acesso a serviços, prestados por tanto tempo quanto necessário (Mowbray et al., 2005).

Na área habitacional, o modelo de habitação apoiada (*supported housing*) veio colmatar problemas encontrados nos modelos de habitação em grupo e de transição, que surgiram na época da desinstitucionalização, nomeadamente a sua incapacidade em facilitar a integração comunitária e a obtenção de habitação estável (Cometa, Morrison & Ziskoven, 1979). A habitação apoiada é um programa que ajuda as pessoas com doença mental a obter habitação independente na comunidade (Rog, 2004). Este programa preconiza que as pessoas tenham acesso a habitação “normal” e estável, da sua escolha (Carling, 1990). Desta forma, existe uma separação de serviços de saúde e habitação, sendo que a pessoa em reabilitação tem acesso a serviços e apoios flexíveis conforme as suas necessidades. De salientar que a colocação na habitação escolhida é imediata, ou seja, não existe uma habitação de preparação/transição (Tabol, Drebing & Rosenheck, 2010).

Desenvolvimento em diferentes partes do mundo

Embora a extensão pela qual a desinstitucionalização ocorreu em diferentes partes do mundo tenha variado bastante, na maioria dos países a reabilitação psiquiátrica surgiu como resposta à desinstitucionalização (Anthony et al., 2002).

Em 1999, Farkas publicou um diretório contendo uma visão global do estado da reabilitação psicossocial em diversas partes do mundo. Resumem-se de seguida os principais achados contidos no respetivo diretório.

Na América do Norte, a década de 1990 foi a década em que a reabilitação psiquiátrica assumiu o seu lugar de direito no triunvirato dos componentes do sistema de saúde mental, isto é, prevenção, tratamento e reabilitação. Nessa década, uma variedade de programas foram comprovados e disseminados (e.g., habitação apoiada, emprego apoiado), começou a existir consenso acerca da filosofia e valores fundamentais da reabilitação psiquiátrica, e formou-se um corpo de conhecimento baseado em evidência científica. Como resultado destes desenvolvimentos positivos, o campo da reabilitação psiquiátrica na América do Norte começou a influenciar a direção de todo o campo da saúde mental (Anthony & Farkas, 1999).

Na Europa, o desenvolvimento de serviços de reabilitação foi muito variável, quer entre países, quer dentro dos próprios países. Contudo, algumas tendências gerais foram observadas. Em primeiro lugar, todos os países lutaram para se afastarem de uma organização de serviços dependentes da provisão habitacional situada em grandes e antigos hospitais psiquiátricos. No entanto, à data da publicação do diretório, os países apresentavam dificuldades em assegurar a existência de um adequado leque de apoio habitacional, ocupacional, social, psicológico e médico na comunidade. Com poucas exceções, há cerca de 10 anos atrás, nenhum país europeu poderia afirmar ter uma cobertura nacional de serviços comunitários abrangentes. As razões desta situação são essencialmente duas: problemas financeiros e dificuldades de cooperação entre agências. Apesar da questão monetária ser mais proeminente nalguns países do que noutros, o facto é que poucos, à época, estavam confiantes de que todo o dinheiro que era anteriormente investido na gestão de hospitais psiquiátricos encontrava redireccionamento para o financiamento de serviços comunitários. Além disso, nessa altura, as pessoas que necessitavam dos serviços de reabilitação apresentavam níveis de insatisfação similares nos diversos países (Shepherd, 1999).

A reabilitação psiquiátrica na Austrália e Nova Zelândia começou de uma forma séria na década de 80 do século passado, embora as pessoas com incapacidades psiquiátricas de longa duração tenham começado a sair das instituições a partir de 1960. A reabilitação na Austrália e Nova Zelândia ocorre principalmente em serviços baseados na comunidade e em pequenas agências. Além disso, o movimento das pessoas com experiência de doença mental é extremamente forte. Aliás, os critérios para o financiamento por parte do governo exigem a participação de pessoas com experiência vivida de problemas de saúde mental na planificação e nos processos de tomada de decisão sobre todos os aspetos da provisão de serviços. Os programas e serviços são integrados em redes com outros serviços, recursos e apoios (Clarke, 1999).

Nalguns países do sudeste asiático, a Lei da Saúde Mental foi criada nos anos 90 do século passado, sendo que nessa altura começaram a surgir serviços baseados na comunidade. No Este Asiático, nas regiões incluindo China, Japão e até certo ponto

Coreia, os programas de reabilitação psicossocial parecem poder ser classificados em 3 categorias: programas isolados desenvolvidos em regiões caracterizadas pela inexistência de cuidados médicos e outros sistemas psicossociais; programas caracterizados pelo suporte de hospitais universitários, que, apesar de serem de grande qualidade, não são integrados numa rede com outros recursos e agências de suporte; e excelentes programas integrados em redes comunitárias (Thara, Deva, & Takashi, 1999).

Em 1999, os países da região africana da Organização Mundial de Saúde estavam a dar os primeiros passos neste campo, encontrando-se a preparar uma estratégia para reduzir a incapacidade associada às perturbações mentais e neurológicas através da reabilitação psicossocial baseada na comunidade (Mandlhate, 1999).

A Reabilitação Psicossocial em Portugal

Breve incursão histórica

Ao contrário das tendências europeias e americanas para a desinstitucionalização das pessoas com doença mental na segunda metade do século XX, em Portugal ainda se criavam, por esta altura, hospitais psiquiátricos, como foi o caso do Hospital Júlio de Matos (1942), do Hospital Sobral Cid (1946) e do Hospital Magalhães Lemos (1962).

A evolução da abordagem dos cuidados de saúde mental em Portugal (e, designadamente, a introdução de serviços de reabilitação de base comunitária) pode ser esboçada nas suas linhas gerais através de uma análise da respetiva legislação.

Em 1945, a Lei 2006/45, de 11 Abril, estabeleceu as bases reguladoras da assistência psiquiátrica. Esta lei previa a divisão do país em três zonas (Norte, Centro e Sul), sendo os cuidados para pessoas com doença mental assegurados em cada zona por um centro de assistência psiquiátrica, que incluía um conjunto de organismos. Além da Direção, os centros eram compostos por um dispensário central, dispensários regionais, hospitais psiquiátricos, clínicas psiquiátricas e asilos psiquiátricos. Os dispensários tinham, entre outras, as funções de desempenhar ações profiláticas e tratar as pessoas doentes em regime ambulatório. Os hospitais psiquiátricos e as clínicas psiquiátricas encarregavam-se de tratar, em regime aberto ou fechado, casos agudos e recentes. Por fim, os asilos psiquiátricos (onde se incluíam as colónias agrícolas) tratavam, geralmente em regime fechado, as doenças de evolução prolongada com o objetivo de "obter a recuperação médica e social dos assistidos, empregando especialmente o método de ocupação e trabalho" (Lei 2006 de 11 de Abril de 1945, p.242). Como verificamos, nesta época, os cuidados à doença mental tinham ainda uma filosofia institucional muito marcada. As experiências de reabilitação (embora o termo não fosse ainda utilizado na legislação) ocorriam no contexto dos asilos psiquiátricos onde se procurava ocupar os internados com atividades (e.g., atividades agrícolas) nas próprias instalações. Considerava-se que a ocupação por si mesma em qualquer atividade, independentemente das capacidades, formação e preferências das pessoas doentes, tinha um efeito estabilizador, evitando a ociosidade e ajudando a inserção na vida da instituição. O trabalho nas oficinas facilitava a "disciplina" dentro das instituições: a ergoterapia ou terapia ocupacional servia a institucionalização dos doentes, não tendo por finalidade o reconhecimento e a valorização das potencialidades de cada um deles.

Passados quase 20 anos, em 1963, a lei n.º 2118 promulgava as bases para a promoção da saúde mental, e ainda que não apelasse a um movimento de desinstitucionalização, preconizava, no âmbito da promoção da saúde mental, a ação recuperadora com vista à integração no meio social. Esta lei previa também a criação de Centros de Saúde Mental, que integravam diversos estabelecimentos e serviços. Entre

1965 e 1980, foram criados 21 Centros com uma cobertura populacional de 60%, o que levou a uma descentralização dos serviços e, por conseguinte, à sua melhor acessibilidade (Direcção-Geral de Saúde, 2004).

Os serviços previstos destinados a adultos já incluíam serviços de reabilitação: “Serviços livres, agrícolas, artesanais ou mistos, como as oficinas protegidas, em que os doentes viverão em regime de comunidade, recebendo uma remuneração pelo trabalho que executam” e “Lares educativos, para reinserção social do ex-doente, que custeará pelo seu trabalho exterior as despesas que fizer no lar” (Lei n.º 2118 de 3 de Abril de 1963, p. 329).

Contudo, a execução prática desta legislação não foi totalmente alcançada e a abordagem hospitalar continuou a dominar os serviços de saúde mental (Alves & Silva, 2004). Além disso, em muitos Centros, os recursos limitados, a dificuldade em fixar profissionais, especialmente no interior, e a integração de instituições asilares foram barreiras ao desenvolvimento de cuidados comunitários (Direcção-Geral de Saúde, 2004).

Nos anos 90, o Decreto-Lei n.º 127/92, de 3 de Julho, extingue os Centros de Saúde Mental existentes e as suas atribuições são transferidas para os Hospitais Gerais, contribuindo, desta forma, para a integração da saúde mental no sistema geral de saúde. Contudo, o desenvolvimento de serviços na comunidade tornou-se praticamente impossível, por dois motivos principais. Primeiro, os hospitais gerais estavam moldados para a prestação de serviços de internamento e continuaram centrados no modelo de internamento. Segundo, as determinações da lei quanto à autonomia financeira e administrativa dos Departamentos de Psiquiatria e Saúde Mental nunca foram cumpridas, não permitindo meios adequados à organização de serviços inovadores (Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental, 2007).

A Lei de Saúde Mental promulgada em 1998 trouxe para esta área avanços importantes, nomeadamente uma preocupação com os direitos das pessoas com doença mental, como sejam, o direito de serem informadas acerca do seu plano terapêutico e de aceitarem ou recusarem as intervenções propostas (salvo nas situações de internamento compulsivo, o qual é também regulado nesta lei). Além disso, a inclusão de membros de associações de utentes e familiares no Conselho Nacional de Saúde Mental veio reconhecer a importância da participação das pessoas com experiência vivida de doença mental no planeamento da política de saúde mental. No entanto, quase dez anos após a promulgação da Lei de Saúde Mental muitas das orientações nela preconizadas continuavam por implementar (Comissão Nacional dos Serviços de Saúde Mental, 2007).

Todavia, a preocupação com a reabilitação psicossocial das pessoas com doença mental surge na Lei de Saúde Mental de 1998, preconizando a prestação de cuidados em estruturas residenciais, centros de dia e unidades de treino e reinserção profissional, localizados na comunidade. Como resultado, no mesmo ano, o Despacho-Conjunto 407/98 propôs a criação de três tipos de respostas habitacionais para pessoas com doença mental: 1) *unidades de vida apoiada* (resposta habitacional, com capacidade média para 20 utentes, destinada a jovens e adultos com doença mental crónica que não conseguem organizar, sem apoio, as atividades de vida diária, mas que não necessitam de intervenção médica frequente); 2) *unidades de vida protegida* (habitação com capacidade para cinco a sete utentes destinada sobretudo ao treino de autonomia de jovens e adultos com doença mental grave e de evolução crónica, clinicamente estável, desde que se afigure possível a integração em programa profissional/ocupacional e que não haja alternativa residencial); 3) *unidades de vida autónoma* (estrutura habitacional, localizada na comunidade com capacidade para cinco a sete jovens e adultos com doença mental severa sem alternativa residencial satisfatória, permitindo a sua integração em programa de formação profissional ou em emprego normal ou protegido). Além das respostas habitacionais, o Despacho 407/98 previa a criação de *Fóruns sócio-ocupacionais*, com vista à reinserção sócio-familiar e sócio-profissional ou à integração em programas de formação ou de emprego protegido das pessoas com doença mental. De acordo com o Instituto da Segurança Social (2009), as respostas supramencionadas terminavam quando o utente atingia estabilidade suficiente para ser autónomo e viver sozinho ou quando reunia condições para voltar a viver com o agregado familiar.

Algumas considerações sobre estas respostas merecem discussão. Apesar destes programas constituírem uma alternativa mais favorável ao internamento hospitalar, alguns aspetos negativos não podem deixar de ser discutidos.

A Equipa de Projecto de Cuidados Continuados Integrados de Saúde Mental (EPCCISM, n.d.) avaliou, entre Julho e Dezembro de 2010, as 57 respostas existentes criadas no âmbito do Despacho-Conjunto nº 407/98. Esta análise demonstrou a existência de um défice na avaliação do desempenho dos profissionais, da qualidade dos serviços prestados e dos resultados obtidos ao longo dos 13 anos de atividade destas unidades. De acordo com a EPCCISM, esta situação levou, em várias instituições, a conformismo e desinvestimento nos projetos de reabilitação, resultando na deterioração da qualidade dos serviços prestados. Os resultados da avaliação da EPCCISM mostraram ainda a existência, devido a dificuldades financeiras, da contratação de profissionais menos qualificados, sem acesso a formação e conhecimento apropriados.

Por outro lado, a literatura internacional tem alertado, nos últimos 30 anos, para os problemas resultantes das respostas habitacionais de transição. Cometa, Morrison e Ziskoven (1979) concluíram que os programas residenciais de transição falham em ajudar as pessoas em adquirir habitação de longo-prazo. De acordo com Carling (1992), estadias temporárias (como é o caso das respostas previstas no Despacho-Conjunto 407/98) podem criar sérias dificuldades para as pessoas com doença mental, induzindo nomeadamente uma necessidade constante de mudança de habitação, uma vez que uma melhoria no funcionamento implica a saída da unidade habitacional e frequentemente um retorno à família (sendo que, por vezes, essa não é a vontade do indivíduo), ou a outro programa residencial, ou ao hospital ou, por vezes, a situações de sem-abrigo.

Além disso, todas as tipologias de habitação previstas no Despacho-Conjunto 407/98 destinam-se a grupos de pessoas com doença mental. No entanto, Tanzman (1993) demonstrou que as pessoas com doença mental preferem viver de forma independente e não com outras pessoas que também sofrem de doença mental.

Outra questão a salientar é o facto de que estas respostas se destinam a pessoas que não têm outra alternativa residencial. Como discutiremos no capítulo 3 da presente tese, ainda que algumas pessoas com doença mental com deterioração significativa possam beneficiar destas respostas, é premente o desenvolvimento de um programa que apoie esta população (sobretudo os jovens), quer tenham ou não suporte familiar, a adquirir habitação independente da sua escolha, com apoio flexível, no mercado normal de habitação. Programas que cumprem estes objetivos são chamados de habitação apoiada (*supported housing*), o que, muitas vezes, gera alguma confusão em Portugal, dado que as unidades de habitação apoiada portuguesas têm uma filosofia exatamente oposta. Note-se ainda que o Plano de Ação para a Reestruturação e Desenvolvimento dos Serviços de Saúde Mental em Portugal 2007-2016, do qual falaremos mais adiante, preconiza o desenvolvimento desta resposta (habitação apoiada), mencionando que se adequa melhor às “necessidades de autonomia, proporcionando uma plena participação na vida social, e simultaneamente assegurando um suporte à integração por uma equipa qualificada” (Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental, 2007, p. 86). Todavia, o estudo nacional descrito no primeiro capítulo mostra-nos que se trata de um programa quase inexistente no nosso país.

O Decreto-Lei n.º 8/2010, posteriormente modificado pelo Decreto-Lei n.º 22/2011, foi aguardado com grande expectativa na medida em que propunha medidas para a criação da Rede de Cuidados Continuados e Integrados em Saúde Mental (RCCISM). Como discutiremos mais adiante na presente tese, a nova legislação acrescentou pouco à reabilitação psicossocial na dimensão habitacional relativamente às respostas existentes ao abrigo do Despacho-Conjunto n.º 407/98. Continuam a ser preconizadas unidades residenciais (residências autónomas, residências com apoio moderado, residências com apoio máximo e residência para treino de autonomia) e alguns dos problemas anteriormente existentes continuam por solucionar. Estas residências são habitações para grupos de pessoas com doença mental e constituem respostas temporárias de habitação, portanto o problema da deslocação crónica é mantido. Mais uma vez, salvo a residência para treino de autonomia, a admissão nas habitações requer que a pessoa com doença mental não tenha suporte familiar ou social. Porém, mesmo existindo suporte familiar, importa perceber que algumas pessoas com doença mental podem preferir tentar viver autonomamente (sobretudo as mais jovens e menos deterioradas pela doença) e, quando tal acontece, é fundamental a prestação de apoio no sentido do alcance desse objetivo, ou seja, ajudar a pessoa a escolher, aceder e viver numa habitação estável. Infelizmente, este tipo de apoio não está previsto na atual legislação.

De facto, um passo importante na nova legislação foi a criação de apoio domiciliário. No entanto, apesar de benéfico para as pessoas com doença mental que vivem sós ou com familiares, o apoio domiciliário, por si só, não resolve o problema dos sem-abrigo, nem evita a desnecessária institucionalização ou colocação em alojamento temporário das pessoas que não têm habitação, bem como não soluciona os casos de permanência involuntária em habitação com familiares. De salientar, no entanto, que Portugal deu passos importantes na prevenção, intervenção e acompanhamento das pessoas sem-abrigo com o lançamento em 2009 de uma estratégia nacional para a integração de pessoas sem-abrigo. Esta estratégia contou, aliás, com a colaboração da Comissão Nacional para a Saúde Mental, designadamente na elaboração do estudo do acesso das pessoas sem-abrigo aos cuidados de saúde mental (Ministério da Saúde, 2012). Uma discussão detalhada a este respeito não se enquadra, contudo, no âmbito da presente tese.

Análise do Plano Nacional para a Reestruturação dos Serviços de Saúde Mental

Um passo importante e cheio de promessas para o campo da Saúde Mental em Portugal foi a criação de um Plano Nacional para reestruturar os serviços de saúde mental entre 2007 e 2016 (Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental, 2007). Este Plano de Ação fundamenta-se em princípios defendidos internacionalmente e considerados cruciais para a prestação de serviços de qualidade, tais como: os serviços de saúde mental devem estar integrados no sistema geral de saúde; as pessoas com perturbações mentais que necessitam de internamento hospitalar devem ser internadas em hospitais gerais; as pessoas com perturbações mentais devem ver respeitados todos os seus direitos, incluindo o direito a cuidados adequados, residência e emprego, assim como proteção contra todos os tipos de discriminação; os cuidados a pessoas com perturbações mentais devem ser prestados no meio menos restritivo possível; as pessoas com perturbações mentais devem ser envolvidas e participar no planeamento e desenvolvimento dos serviços de que beneficiam; os familiares de pessoas com perturbações mentais devem ser considerados parceiros importantes na prestação de cuidados de saúde mental; os serviços de saúde mental devem criar condições que favoreçam a auto-determinação das pessoas com problemas de saúde mental por intermédio da procura de um caminho próprio de desenvolvimento pessoal (Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental, 2007, p. 62).

De acordo com a Reatualização do Plano Nacional de Saúde Mental (Ministério da Saúde, 2012), o Plano assegurou já progressos significativos: o número de doentes institucionalizados em hospitais psiquiátricos diminuiu 40%; foi encerrado o mais antigo hospital psiquiátrico do país, ao mesmo tempo que foi preparada a desativação de outros. No entanto, e apesar dos esforços despendidos, a persistência de um sistema de financiamento centrado ainda na prestação de cuidados institucionais, não encorajando, por conseguinte, o desenvolvimento de cuidados na comunidade, continua a ser um forte obstáculo ao progresso dos cuidados de saúde mental. A OMS procedeu a uma avaliação detalhada do Plano Nacional de Saúde Mental em 2011, sendo que na análise efetuada salientam-se os seguintes pontos negativos dos serviços locais de saúde mental portugueses: continua a haver áreas geográficas sem cobertura destes serviços e os cuidados prestados nos mesmos são principalmente de tipo farmacológico, verificando-se a escassez de respostas psicossociais (Ministério da Saúde, 2012).

Os programas profissionais

Um dos programas existentes no nosso país para responder à dificuldade de inserção profissional de grupos vulneráveis, onde se incluem as pessoas com doenças psiquiátricas, são as empresas de inserção, definidas como “as pessoas coletivas sem fins lucrativos que tenham por fim a reinserção sócio-profissional de desempregados de longa duração ou em situação de desfavorecimento face ao mercado de trabalho" [Portaria n.º 348-A/98 de 18 de Junho, p. 2762-(3)]. As empresas de inserção, análogas às empresas sociais, funcionam segundo modelos de gestão empresarial, mas flexibilizam os ritmos e organização do trabalho de acordo com as características dos seus trabalhadores. No entanto, ao contrário do que acontece nas empresas sociais descritas na literatura científica especializada, não está explícito na legislação portuguesa se as pessoas pertencentes aos grupos vulneráveis têm oportunidade de desempenhar postos de gestão. Aliás, a legislação preconiza que "as empresas de inserção devem dispor de técnicos para as áreas administrativas e de gestão (…)" [Portaria n.º 348-A/98, p. 2762-(3)].

As empresas sociais no estrangeiro preconizam a existência de trabalhadores nos variados postos da empresa, quer tenham quer não tenham qualquer tipo de incapacidade, promovendo, assim, uma verdadeira experiência de inclusão social. Trata-se de uma situação que não está explicitamente prevista na nossa legislação e que, não acontecendo na prática, traduz, em certa medida, uma forma de estigma e exclusão. Não integrando nas empresas pessoas com e sem vulnerabilidade nos mais variados postos faz com que a sua distinção dos centros de emprego protegido, considerados atualmente segregadores (Leff & Warner, 2006), não seja clara.

A legislação portuguesa refere que os grupos desfavorecidos face ao emprego "juntam a níveis muito baixos de habilitações escolares (…) desvantagens acrescidas por auto-imagens desvalorizadas, estigmatização e estatutos sociais negativos (…) e ainda problemas específicos de saúde, dependência de drogas, álcool e deficiência" [Portaria n.º 348-A/98 de 18 de Junho, p. 2762-(29)]. De facto, no caso das perturbações psiquiátricas, que são o alvo da nossa discussão, o estigma a elas associado, bem como a auto-confiança e auto-estima baixas, constituem fortes barreiras ao emprego. Contudo, nem todas as pessoas com doenças mentais têm níveis baixos de habilitações escolares, mas nem por isso deixam de ser um grupo desfavorecido face ao emprego. Por conseguinte, os postos de trabalho num programa de reabilitação psicossocial devem ser adaptados às características individuais de cada pessoa, possibilitando-se o total desenvolvimento do seu potencial. Não obstante estes aspetos, que devem ser levados em conta pelos seus promotores, as empresas sociais são, sem dúvida, uma forma efetiva de combate ao desemprego e exclusão social de pessoas em situação de vulnerabilidade, ao mesmo tempo que criam um produto ou serviço socialmente útil.

O Decreto-Lei 290/2009, de 12 de Outubro, veio criar o Programa de Emprego e Apoio à Qualificação das Pessoas com Deficiências e Incapacidades, tentando sistematizar e inovar as medidas anteriores de reabilitação profissional (previstas em legislação da década de 80, nomeadamente o Decreto-Lei n.º 247/89, de 5 de Agosto, bem como o Decreto-Lei n.º 40/83, de 25 de Janeiro). Esta nova legislação inclui como beneficiários dos programas as pessoas com incapacidades, sendo que na legislação da década de 80 as respostas previstas eram direcionadas apenas às pessoas com deficiências (ainda que muitas instituições incluíssem nos programas criados ao abrigo desta legislação pessoas com doença mental). O Programa de Emprego e Apoio à Qualificação das Pessoas com Deficiências e Incapacidades compreende medidas de apoio à qualificação; apoios à integração, manutenção e reintegração no mercado de trabalho; emprego apoiado; e prémio de mérito.

O apoio à qualificação é realizado através de ações de formação, as quais podem ser integradas no contexto das ações destinadas à população geral, bem como através de ações especificamente destinadas às pessoas com deficiências e incapacidades, que mesmo com adaptações do meio não possuem condições para participar nas primeiras.

Sabemos que muitas pessoas com doença mental em Portugal frequentam ações de formação específicas para pessoas com incapacidades (capítulo 1). No entanto, e apesar de admitirmos que possa ser uma medida adequada para outros grupos, no caso da doença mental, sobretudo em faixas etárias mais jovens, a inclusão no sistema geral de ensino só é, na maior parte das vezes, impossibilitada pela falta de suporte adequado.

A integração, manutenção e reintegração no mercado de trabalho das pessoas com deficiências e incapacidades integra as seguintes modalidades: a) Informação, avaliação e orientação para a qualificação e emprego; b) Apoio à colocação; c) Acompanhamento pós-colocação; d) Adaptação de postos de trabalho e eliminação de barreiras arquitetónicas; e) Isenção e redução de contribuições para a Segurança Social.

A informação, a avaliação e a orientação para a qualificação e o emprego têm como objetivos apoiar as pessoas com deficiências e incapacidades na tomada de decisões vocacionais adequadas, bem como no desenvolvimento do seu plano pessoal de emprego.

O apoio à colocação visa promover a integração no mercado de trabalho das pessoas com deficiências e incapacidades, através de um processo de mediação entre as mesmas e as entidades empregadoras. Esta medida pressupõe quer a sensibilização das entidades empregadoras para os benefícios resultantes da contratação desta população, quer o apoio ao destinatário na procura ativa de emprego e na criação do próprio emprego (este programa tem um período máximo de duração de seis meses para cada destinatário, para efeitos de comparticipação financeira do Instituto de Emprego e Formação Profissional com os custos resultantes da intervenção).

O acompanhamento pós-colocação consiste no apoio às pessoas com deficiências e incapacidades e respetivas entidades empregadoras, tendo em vista a manutenção no emprego e a progressão na carreira. O período máximo de duração das ações de acompanhamento pós-colocação é de 12 meses para cada trabalhador com deficiências e incapacidades, podendo ser, em situações excecionais, prorrogado até ao limite de 24 meses. O acompanhamento pós-colocação é ainda aplicável aos destinatários inseridos em estágios financiados pelo Instituto de Emprego e Formação Profissional, em qualquer das modalidades de contrato emprego-inserção ou no contrato de emprego apoiado em entidades empregadoras. Estas ações têm a seguinte duração máxima: no caso dos estágios ou qualquer das modalidades de contrato emprego-inserção, o acompanhamento pós-colocação tem o período de realização das mesmas; no caso do contrato de emprego apoiado em entidades empregadoras, 36 meses, podendo excecionalmente ser prorrogado quando existam razões fundamentadas.

Feita esta descrição das três primeiras medidas de apoio à integração, manutenção e reintegração no mercado de trabalho previstas no Programa de Emprego e Apoio à Qualificação das Pessoas com Deficiências e Incapacidades, importa ter consideração que estes prazos para o término das diferentes ações não se coadunam com a evidência respeitante à integração das pessoas com doença mental no mercado normal de trabalho, as quais necessitam de apoio contínuo por tempo indeterminado. Segundo Bond (2004), o apoio deve ser prestado até que se verifique a necessidade do mesmo e não apenas durante prazos arbitrariamente definidos. Becker, Whitley, Bailey e Drake (2007) realizaram um estudo exploratório acerca das trajetórias de adultos com incapacidade psiquiátrica que participaram em emprego apoiado. Os autores voltaram a entrevistar 38 de 78 participantes com doença mental severa, oito a doze anos após terem beneficiado de emprego apoiado. No período de *follow-up*, a grande maioria (82%) trabalhava em emprego competitivo, sendo o apoio contínuo um dos maiores facilitadores. Por seu turno, Salyers, Becker, Drake, Torrey, & Wyzik (2004) realizaram um estudo de *follow-up* da conversão de um programa de tratamento de dia para emprego apoiado verificando que 86% dos utentes estavam ainda a receber serviços dez anos mais tarde. Além disso, as pessoas com doença mental empregadas no *follow-up* atribuíram boa parte do seu sucesso ao apoio contínuo dos profissionais.

O Decreto-Lei 290/2009 define emprego apoiado como:

> O exercício de uma atividade profissional ou socialmente útil com enquadramento adequado e com possibilidade de atribuição de apoios especiais por parte do Estado, que visa permitir às pessoas com deficiências e incapacidades o desenvolvimento de competências pessoais e profissionais que facilitem a sua transição, quando possível, para o regime normal de trabalho. (p. 7489)

Nos Estados Unidos, o sentido do termo "emprego apoiado", aceite em diferentes partes do mundo, refere-se, por um lado, a um estatuto de emprego e, por outro, a um programa de emprego. Como estatuto de emprego, o termo refere-se a emprego competitivo para indivíduos com incapacidades relevantes trabalhando em serviços consistentes com as suas forças, recursos, prioridades, capacidades, interesses, e escolha informada, para quem o emprego competitivo não ocorre tradicionalmente ou para quem o emprego competitivo tenha sido interrompido em resultado da incapacidade (Rehabilitation Act Amendments, 1998, referido por Bond, 2004). Como prática, o emprego apoiado refere-se a programas com vista a ajudar pessoas com incapacidade a encontrar e manter este tipo de emprego (Bond, 2004). Isto significa que programas que não tenham um enfoque direto na procura e manutenção de emprego competitivo não podem, por definição, ser considerados programas de emprego apoiado.

A legislação portuguesa defende que o emprego apoiado pode ser desenvolvido nas seguintes modalidades: a) estágio de inserção para pessoas com deficiências e incapacidades; b) contrato emprego-inserção para pessoas com deficiências e incapacidades; c) centro de emprego protegido; d) contrato de emprego apoiado em entidades empregadoras.

Os estágios de inserção visam apoiar a integração ou reintegração no mercado de trabalho de pessoas com deficiências e incapacidades, através de formação prática em contexto laboral, de forma a facilitar o seu recrutamento e melhorar o desempenho profissional. Esta definição vai mais ao encontro do programa de emprego de transição, precursor do emprego apoiado, que tem como objetivo dotar o paciente com as competências básicas de trabalho que o capacitarão a passar para um posto permanente não apoiado em mercado normal de trabalho (Leff, 2008).

O contrato de emprego-inserção pretende apoiar a transição para o mercado de trabalho das pessoas com deficiências e incapacidades, através de atividades socialmente úteis, que promovam hábitos de trabalho e competências relacionais e pessoais.

No entanto, o que nos parece mais gritante é a legislação considerar o emprego protegido [definido como “a estrutura produtiva dos sectores primário, secundário ou terciário com personalidade jurídica própria ou a estrutura de pessoa coletiva de direito público ou privado, dotada de autonomia administrativa e financeira, que visa proporcionar às pessoas com deficiências e incapacidades e capacidade de trabalho reduzida o exercício de uma atividade profissional e o desenvolvimento de competências pessoais, sociais e profissionais necessárias à sua integração em regime normal de trabalho”, Decreto-lei 290/2009 de 12 de Outubro, p. 7490] como uma modalidade de emprego apoiado, quando a literatura internacional nos mostra claramente que são dois programas distintos e, aliás, com filosofias opostas. De acordo com a literatura internacional, o emprego protegido refere-se ao desenvolvimento de postos de trabalho fora do mercado normal de trabalho (tal como o nome indica, “protegidos” dos requisitos do mercado competitivo) e o emprego apoiado caracteriza-se como a colocação rápida em emprego competitivo, fornecendo o apoio e formação necessários para a pessoa manter esse posto (Leff & Warner, 2006). Saliente-se que no emprego apoiado o treino de competências é fornecido sobretudo após a colocação e não como um passo preparatório, ou seja, trata-se de uma abordagem colocação-formação, contrariando a prática da enfatização da avaliação e formação pré-vocacional (Becker, Drake, Naughton, 2005).

Além disso, a evidência científica sugere que o emprego protegido não favorece, e até pode bloquear, a colocação em emprego competitivo (Bond, 2004), que é o foco essencial de um programa de emprego apoiado. Os críticos argumentam que as pessoas colocadas em serviços de baixa exigência podem falhar no avanço para um trabalho mais desafiador, mesmo que sejam capazes de o fazer (Lehman, 1995).

A última modalidade de emprego apoiado prevista na legislação é o contrato de emprego apoiado em entidades empregadoras, ao abrigo do qual as pessoas com deficiências e incapacidades desenvolvem uma atividade profissional num meio normal de trabalho sob condições especiais, designadamente sob a forma de enclaves. Um enclave define-se como um grupo de pessoas com deficiências e incapacidades que exercem a sua atividade em conjunto num meio normal de trabalho. Ora, os enclaves são uma outra forma de emprego protegido, tal como já preconizava o Decreto-Lei n.º 40/83 de 25 de Janeiro.

Por conseguinte, esta diferença de nomenclatura em nada abona a favor do desenvolvimento dos serviços, querendo significar, por vezes, a falta de atenção que é devida não só ao que se faz em países com sistemas de cuidados de saúde mental mais aperfeiçoados do que o nosso mas também ao que é esperado de acordo com o "estado da arte".

O Diretório *International practice in psychosocial/psychiatric rehabilitation* (Farkas, 1999) define características mínimas de boas práticas em reabilitação psicossocial/psiquiátrica. Uma dessas características é a de que os programas foquem a população com doenças mentais severas. Apesar de existirem bons programas de reabilitação para outras populações com incapacidades, a reabilitação psicossocial/psiquiátrica tem que ter as pessoas com doença mental severa como a sua população prioritária.

Assim, o problema do Decreto-Lei 290/2009 é direcionar as medidas de apoio ao emprego para a vasta população de pessoas com deficiências e incapacidades, não levando em conta as especificidades dos diferentes grupos que se encontram aí contemplados. Ainda que as medidas propostas possam constituir respostas adequadas para grupos com determinadas incapacidades, o facto é que a legislação apresenta sérias fragilidades e inconsistências quanto à reabilitação profissional das pessoas com doença mental severa. Tal como referido anteriormente, foi desenvolvido nos anos 90 do século passado um programa de emprego apoiado específico para as pessoas com doença mental, o modelo de colocação e apoio individuais, o qual não está previsto na legislação portuguesa e em relação ao qual existe um grande desconhecimento no nosso país (capítulo 1). Mas mesmo o próprio emprego apoiado não se encontra legislado de acordo com o que nos mostra a evidência científica. As mais recentes recomendações na área da reabilitação psicossocial de pessoas com esquizofrenia da PORT (*Patient Outcomes Research Team*), baseadas em ensaios clínicos suficientes, preconizam que a qualquer pessoa com esquizofrenia que tenha o objetivo de trabalhar deve ser oferecido emprego apoiado, principalmente colocação e apoio individuais (*individual placement and support*), no sentido de a ajudar na obtenção e manutenção de emprego competitivo (Dixon et al., 2010). Sublinhamos, portanto, a necessidade de se criar legislação específica para as pessoas com doença mental que leve em conta as recomendações internacionais. A questão da legislação é crucial em Portugal, uma vez que grande parte dos projetos de reabilitação vocacional para pessoas com doença mental severa são promovidos por Instituições Privadas de Solidariedade (IPSS), sendo que respostas não enquadradas na legislação muito dificilmente recebem apoios financeiros para a sua implementação.

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Capítulo 1

Psychosocial/Psychiatric Rehabilitation in Portugal:

A national survey

Abstract

Background: The National Commission for the Restructuring of Mental Health Services published in 2007 an Action Plan to develop and restructure the Portuguese mental health system, foreseeing, among other measures, the implementation of psychosocial/psychiatric rehabilitation programs. Objective: To report on the current existent psychosocial rehabilitation programs in Portugal. Methods: A survey was sent to 70 institutions throughout Portugal questioning if they provided different types of psychiatric rehabilitation programs in the areas of work, education, housing, occupational activities and family support. A description of the indicated programs was requested. Descriptive statistics were carried out with SPSS 20.0. Results: We obtained a response rate of 40%. In the area of education, 35.7% of the institutions had non-mainstream vocational training courses, while just 14.3% provided supported education services. Regarding vocational rehabilitation, the scenario was: 7.1% of the institutions provided sheltered work, 25% had social firms, and 28.6% offered supported employment services, but none provided the individual placement and support model of supported employment. The most frequent program in the area of housing was permanent group homes in the community, provided by 28.6% of the institutions surveyed, followed by transitional group homes located within the grounds of the institutions (17.9%). Supported housing services were provided by only 14.3% of the institutions. Finally, 92.9% of the institutions offered occupational activities services, 60.7% provided multi-family psychoeducation and 35.7% provided single-family psychoeducation.

Conclusions and Implications for Practice: The only evidence-based program which is reasonably implemented is multi-family psychoeducation. Supported employment, especially individual placement and support, supported education and supported housing are still poorly disseminated. It is imperative that professionals and legislators on the field keep up to date with international recommendations on psychiatric rehabilitation in order that evidence and value based programs are implemented in our country.

Key words: psychiatric rehabilitation, mental illness, survey

Introduction

The Action Plan for the restructuring of mental health services in Portugal [Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental, CNRSSM (National Commission for the Restructuring of Mental Health Services), 2007] recommends the deinstitutionalization of people with severe mental illness and the implementation of psychiatric/psychosocial rehabilitation services. Six years after the publication of this Action Plan, it is of utmost importance to assess the practical execution of these recommendations.

Previous studies demonstrated insufficiencies in the area of psychosocial rehabilitation in our country. A study carried out by Marques, Queirós and Rocha (2006) assessed 13 institutions working in the psychiatric rehabilitation field and verified that most of the rehabilitation services provided were professional training.

The National Commission for the Restructuring of Mental Health Services (CNRSSM, 2007) adapted the *World Health Organization Assessment Instrument for Mental Health Systems* (WHO-AIMS) to be used in Non-governmental Organizations (NGOs) in Portugal. The questionnaire was sent to 62 Organizations for data collection on their characteristics and interventions provided. Data from 38 Organizations (61%)

were obtained. Results showed a great increment in the creation of NGOs from the beginning of the 90s, the majority with the status of Private Institution for Social Solidarity (Instituição Privada de Solidariedade Social, IPSS). Regarding the psychosocial interventions provided by these institutions, occupational activities, individual counseling, social support, job search support and skills training were the most common. The less frequent interventions provided by the Organizations were supported employment, integration firms (social firms) and educational support (although it is not explained what is meant by educational support).

The Commission also assessed the programs created under the Joint Order n.º 407/98 (dated June 18, 1998), which are group living residential facilities with 3 different levels of support (autonomous living units, sheltered living units, and supported living units) and socio-occupational forums. The supported living unit (defined as a residential facility with capacity for 20 users with chronic mental illness who are not able to organize without support the activities of daily living, but who do not need frequent medical intervention) had 48 places and 66 persons on the waiting list. Sheltered living units (residential facility, designed for autonomy training, for five to seven users, clinically stable and with no other residential alternative, who present conditions to integration into professional or occupational program) had 92 places and 135 persons on the waiting list. The autonomous living units (defined as housing, located in the community for five to seven persons with severe mental illness with no satisfactory residential alternative, allowing their integration either into a vocational training program, or in mainstream or sheltered employment) had 14 places and nobody on the waiting list (CNRSSM, 2007). It is noteworthy that these residential facilities are temporary and the user should leave when reaching sufficient stability to be independent and live alone or when meeting conditions to return to live with the family (Instituto da

Segurança Social, 2009). The Joint Order n.º 407/98 also provides for the development of socio-occupational forums, defined in the legislation as a small facility aiming the social, family and/or professional reintegration of persons disadvantaged by mental illness or their eventual integration into training programs or sheltered employment. The National Commission for the Restructuring of Mental Health Services (CNRSSM, 2007) found that there was in total 469 places in the social-occupational forums and 56 persons on the waiting list.

In 2011, the World Health Organization carried out a detailed evaluation of the National Mental Health Plan implementation and verified a lack of psychosocial interventions and the predominance of pharmacological treatment in the Portuguese local mental health services (Ministério da Saúde, 2012).

Taking into account this reality, it is crucial to assess what types of psychiatric rehabilitation programs are currently provided to people with severe mental illness in Portugal. We aimed to evaluate to what extent evidence-based practices like the individual placement and support model of supported employment (IPS, Drake et al., 1994; Drake, McHugo, Becker, Anthony, & Clark, 1996) and family psychoeducation (Leff, 2005; Mueser, Deavers, Penn, & Cassisi, 2013) are implemented in our country. We also assessed the existence of promising and value-based practices such as supported education (Mowbray et al., 2005) and supported housing (Rogers, Kash-MacDonald, & Olschewski, 2009). The existence of other programs, less recommended in the international literature and demonstrated to create some difficulties to people with mental illness, such as transitional group homes, was also assessed.

Methods

A survey was sent to 70 institutions throughout Portugal, including the mainland and the archipelagos of Madeira and Azores. We reached this number of institutions as following. We found in the website “Recovery Network” (http://www.recoverynetwork.labrp.com/) a list of the Portuguese institutions that work in the mental health field. The “Recovery Network” was developed by the Laboratory of Psychosocial Rehabilitation which is affiliated with the School of Health Technology of Porto Polytechnic Institute and the Faculty of Psychology and Educational Sciences of the University of Porto. The “Recovery Network” is a website forum developed with the co-funding of the National Institute for Rehabilitation and aims to link individuals and Organizations with interest in the recovery of people with lived experience of mental illness, and to facilitate the sharing of experiences, information and knowledge. The website contains a list of the Portuguese mental health institutions, composed of 31 institutions of the National Health Service and 39 Private Institutions for Social Solidarity (Instituições Privadas de Solidariedade Social, IPSSs). We removed from the list the 3 Services of Pedopsychiatry and two IPSSs (one working exclusively with people with post-traumatic stress disorder and the other one exclusively with people with obsessive compulsive disorder). We grouped a Department of Psychiatry of a General Hospital with a Psychiatric Hospital that currently belong to the same institution and are under the same management and also grouped two units of the same Department of Psychiatry that appeared separately in the list. We added 3 NGOs from the archipelago of Azores and Madeira that did not figure in the list of the Recovery Network website. We also added 2 Nonprofit Associations and 2 Psychiatric Hospitals.

So, in total we sent the survey to 70 institutions: 30 public institutions, composed by 27 Departments and Services of Psychiatry of General Hospitals (one of them grouped with a Psychiatric Hospital) and 3 Psychiatric Hospitals; and 40 Non-governmental Organizations: 2 with the status of Nonprofit Association and 38 with the status of Private Institution for Social Solidarity (IPSS). 13 of the IPSSs are Religious Institutions.

Data collection was carried out from January 2013 to August 2013. In a first phase, the survey was sent by mail to all institutions. As a response to our letter with the questionnaire enclosed, we received 13 responses. So, in a second phase we contacted institutions by e-mail and through social networks (those that we verified that had a *facebook* page). After this contact, we received 8 responses. We then sent e-mails and contacted institutions through social networks a third time and received 7 more responses. We note that during data analysis participating institutions were contacted several times either by e-mail or phone in order to ask for clarification regarding some doubts which were appearing.

The survey was created by our team and is composed by multiple choice questions, closed-ended questions and open-ended questions. First of all, it was explained the goals of the study and stated that the questionnaire should be answered by the Directors/Chiefs of the rehabilitation services of Psychiatric Hospitals, Departments and Services of Psychiatry of General Hospitals, Nonprofit Associations, Private Institutions for Social Solidarity, Religious Institutions and other Organizations providing psychosocial rehabilitation services. The first question of the survey requested the identification of the institution type, whether it was a Psychiatric Hospital, a Department of Psychiatry of a General Hospital, a Private Institution for Social Solidarity (IPSS), a Nonprofit Association or a Religious Institution.

Secondly, it was asked how many professionals were involved in the rehabilitation activities: psychiatrists, psychologists, nurses, social workers, occupational therapists and others.

The areas of rehabilitation in analysis were: educational rehabilitation; vocational rehabilitation; residential rehabilitation; occupational activities; psychoeducation for families/informal carers.

In educational, vocational and housing areas, institutions were given a group of programs and asked to tick which of them they offered. In the area of education, the options were supported education, professional training specific for people with mental illness (or specific for people with disabilities) or other (if other, which). Concerning professional rehabilitation, the options were sheltered work, supported employment, individual placement and support, social firms and other (if other, which). In the housing domain, the alternatives were group homes and supported housing. Regarding group homes, institutions were asked if they were located in the community and if they were permanent or transitional. Being aware that the term supported housing would lead to confusion and would be associated to supported living units (staffed group homes provided for in the Portuguese legislation), we asked if institutions had a program to help individuals in the access to independent housing in the community/normal housing market with flexible supports. In order to better understand the housing services provided, institutions were asked the following questions regardless of the indicated program: do the users choose the house? (or is the placement made according to existent vacancies?); does the institution/hospital own the house?; how many users live in the house?; how often professionals visit the house?.

After each of the aforementioned three areas of rehabilitation, there was an open-ended question asking institutions to explain and describe the indicated programs and whether the programs were designed to people with mental illness (in order to verify if the description corresponded to the indicated program).

The survey also questioned if the institution provided occupational activities and if yes what kind of occupational activities. Finally, it was asked if family psychoeducation was provided and if yes whether it was multi or single family.

Concerning data analysis, descriptive statistics were carried out with SPSS 20.0. The analysis of the qualitative descriptions of the programs asked in the open-ended questions was made by the author who checked if the description given corresponded to the indicated program in the multiple choice questions. For example, the description of supported education should mention that the program supports the access to mainstream education; supported employment description should mention that the program supports people with mental illness to obtain and maintain a job in the mainstream labor market; the individual placement and support program description should make reference to its principles (services focused on competitive employment; eligibility based on consumer choice; rapid job search; rehabilitation is integrated in mental health team; attention to consumer preferences; time-unlimited and individualized support; benefits counseling); a program was considered supported housing if the description involved the support in the access to a stable/permanent independent house in the normal housing market, with flexible supports, of the choice of the person who receives the service.

Results

We received responses from 28 institutions (40%): 6 public institutions and 22 Non-governmental Organizations. The 6 public institutions (21.4% of the total sample) were Departments/Services of Psychiatry of General Hospitals. Non-governmental Organizations encompassed 10 (35.7% of the total sample) Private Institutions for Social Solidarity (IPSSs), 5 (17.9% of the total sample) Nonprofit Associations (we note that 3 of them were characterized in the Recovery Network website as Private Institutions for Social Solidarity, but they stated in the survey that they had the status of Nonprofit Associations), and 7 (25% of the total sample) were Religious Institutions (which are Private Institutions for Social Solidarity as well). In terms of geographic location, 6 institutions (21.4%) were from the North, 11 (39.3%) from the Center, 9 (32.1%) from the South (it is noteworthy that 8 of the institutions of the South are located in the Lisbon and Tagus Valley region and 1 is located in Algarve), and 2 (7.1%) from Madeira Island. We did not receive responses from Azores.

3 Private Institutions for Social Solidarity (IPSSs) and 3 Associations did not have mental illness as their only or many focus, providing services to other vulnerable populations such as people with intellectual issues. Moreover, one IPSS focused just people with depression and bipolar disorders. All Religious Institutions (which also have the status of Private Institution for Social Solidarity as we mentioned before) offered services to vulnerable groups other than mental illness (e.g., people with intellectual problems and elderly).

Public institutions (N = 6) had a mean number of programs of M= 2.8 SD=2.0 and Non-governmental Organizations (N=22) had a mean number of programs of M=5.0 SD=1.9.

In table 1. we show the mean number of professionals involved in the rehabilitation activities. We note that one institution did not provide data on this matter and one institution had a much superior number of professionals (216 professionals in total, 41 nurses, and 163 other professionals) than the rest, so that they were not included in the analysis.

Table 1. Mean number of professionals involved in the rehabilitation activities in the institutions surveyed (N=26).

	M	SD
Total number of professionals	14.1	12.1
Psychiatrists	0.9	1.5
Psychologists	2.2	1.9
Nurses	2.6	4.2
Social Workers	1.3	1.2
Occupational Therapist	1.2	2.3
Other professionals (e.g., auxiliaries, monitors)	6.0	9.4

Educational rehabilitation

10 institutions (35.7%) mentioned having non-mainstream vocational training courses (7 institutions had non-mainstream courses for the heterogeneous population of people with disabilities and 3 institutions had non-mainstream courses specific for people with mental illness). From these 10 institutions, 5 were located in the Lisbon and Tagus Valley region, 4 were located in the Central region and 1 was located in Madeira Island. Classes of these non-mainstream training courses were mainly delivered in the premises of the institutions (3 Religious Institutions, 2 IPSSs, 2 Associations, and 2

Departments/Services of Psychiatry). We note that 1 IPSS stated having courses specific for people with disabilities but that these courses took place in normal businesses/firms. Another institution provided training courses for people with disabilities with the specific goal of integrating them into social firms.

4 institutions (14.3%) had supported education: 2 located in Porto (North and second larger city), 1 in Lisbon (Capital), and 1 in Barreiro (Lisbon and Tagus Valley region). The 4 institutions were Private Institutions for Social Solidarity (IPSS). Two of them did not indicate supported education in the multiple choice question, but their description led us to consider that they provide, in fact, services of supported education. One of the institutions said they support the access to mainstream courses and the other one mentioned that in the ambit of the Academic, Professional and Occupational Integration Office, they have partnerships with educational institutions and promote specific competences to support the integration into these institutions according to the educational goals of each person. 4 institutions said they had other rehabilitation programs in the area of education, but the programs indicated by 3 of them and their description did not correspond in fact to psychosocial/psychiatric rehabilitation services. Edition of scientific documentation on mental health, organization of seminars, training for mental health professionals, occupational activities were responses indicated as educational rehabilitation and which we did not consider as such. 1 institution indicated in the field “other program” classes for educational support, but no further description of these classes was given.

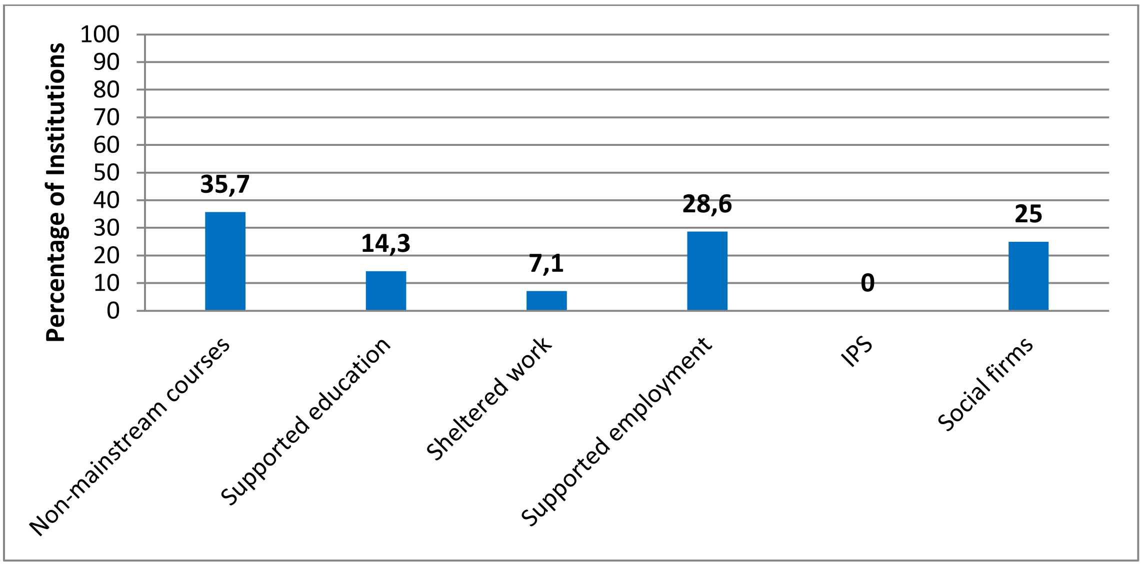
Vocational rehabilitation

Regarding vocational rehabilitation, 2 (7.1%) institutions had sheltered work (both in the Central region, 1 with the status of IPSS and 1 with the status of Nonprofit Association) and 8 (28.6%) had supported employment (3 from the North, 2 from the Center and 3 from the Lisbon and Tagus Valley region; 5 were IPSSs, 2 were Associations, and 1 was a Department/Service of Psychiatry of a General Hospital). We note, however, that 3 institutions did not indicate supported employment in the multiple choice question, but according to the descriptions of services, we classified them as having supported employment services. Descriptions included for example "*Support in the active search for job. After placement in the normal labor market, the therapist supports and monitors the integration of the person with mental illness and works with employers (with the consent of the consumer)*". 9 institutions indicated in the multiple choice question that they had individual placement and support (IPS); however, none of the descriptions made reference to the principles of IPS and, in fact, did not correspond to the actual IPS program, so no institution of our study delivered individual placement and support. 7 (25%) institutions had social firms (5 located in the Central region and 2 located in the Lisbon and Tagus Valley Region; the 7 institutions were Non-governmental Organizations: 4 IPSS, 2 Associations and 1 Religious Institution). One institution did not indicate in the multiple choice that had a social firm, but in the description said that there was a pastry firm in the institution, being users responsible for its operation, for the pastry confection and for supplying pastries to the bar and units of the institution.

5 institutions indicated they had other types of vocational rehabilitation, namely integration internships and employment-integration contracts (services provided for in the Portuguese legislation on the Employment Program and Support to the Qualification

of Persons with Deficiencies and Disabilities), professional integration office (service in partnership with the Employment Center for people with and without mental illness, providing, for example, sessions on active job search techniques), psychosocial support (defined as individual and family support, inter-institutional coordination, community awareness), and vocational counseling.

Graph 1 – Percentage of institutions providing educational and vocational rehabilitation programs.



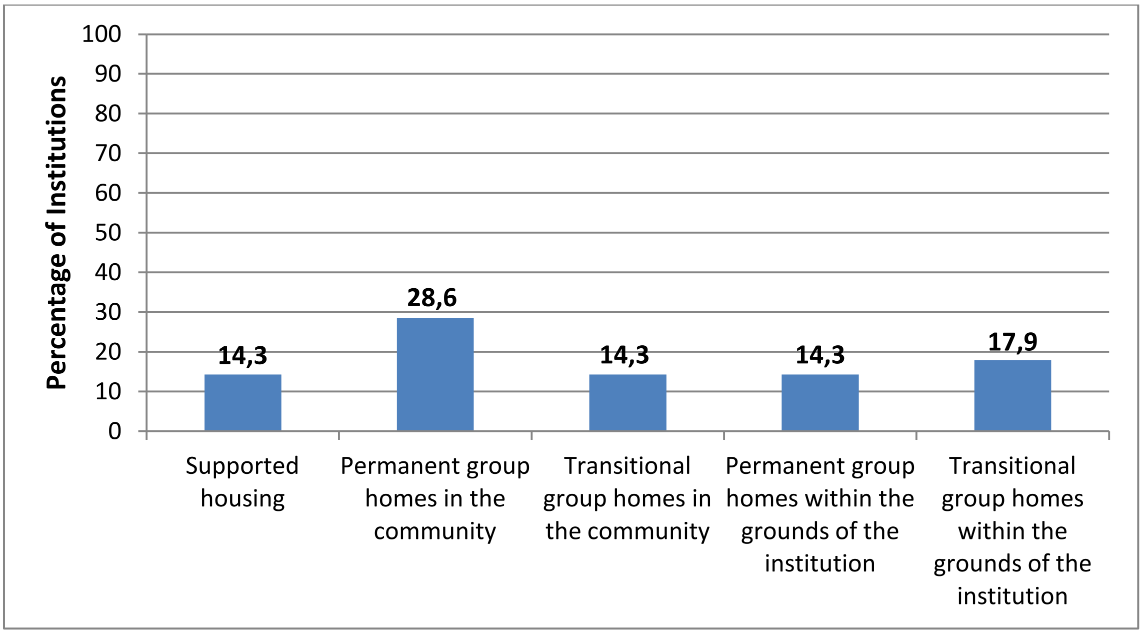
Residential rehabilitation

4 (14.3%) institutions had supported housing (1 from the North, 1 from the Center, and 2 from the Lisbon and Tagus Valley region; 2 were IPSS and 2 were Associations). As we mentioned before, we did not use the term “supported housing” in the multiple choice, but rather its definition, in order to avoid confusion with supported living units, which are staffed group homes in Portugal.

8 institutions (28.6%) had permanent group homes in the community (5 Religious Institutions, 2 IPSS, and 1 Department/Service of Psychiatry of a General Hospital; 3 from the Lisbon and Tagus Valley region, 3 from the Center, 1 from the North, and 1 from Madeira Island). 4 institutions (14.3%) had transitional group homes in the community (1 Department/Service of Psychiatry of a General Hospital, 1 IPSS, and 2 Religious Institutions; 1 from the North, 1 from the Center, 1 from Madeira Island and 1 from Lisbon and Tagus Valley). 4 institutions (14.3%) had permanent group homes within the grounds of the institution (1 IPSS, 1 Association, and 2 Religious Institutions; 2 from the Center, 1 from the Lisbon and Tagus Valley region, and 1 from Madeira Island). 5 institutions (17.9%) had temporary/transitional group homes within the grounds of their buildings (the 5 institutions were Religious Institutions; 1 from the North, 2 from the Center, 1 from the Lisbon and Tagus Valley region, and 1 from Madeira Island).

Although it was not directly asked, 4 institutions (14.3%) mentioned having domiciliary care.

Graph 2 – Percentage of institutions with different types of housing support services



Occupational activities

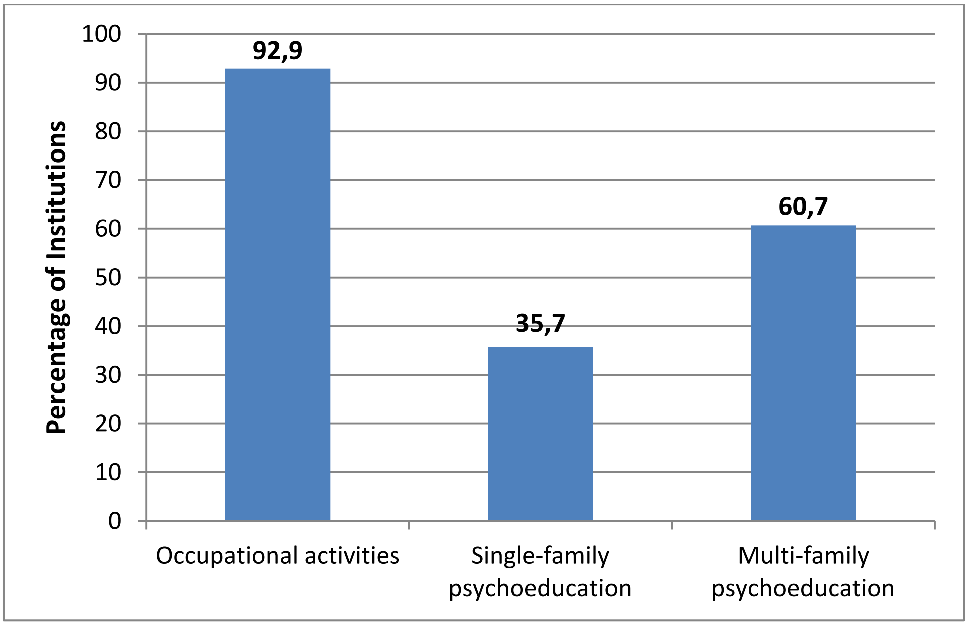
26 institutions (92.9%) mentioned having occupational activities. Examples of occupational activities mentioned by institutions included: painting, craftwork, carpentry, weaving, music, singing, dancing, theater, creative writing, sports (1 institution referred the utilization of a community sport centre available for the general population), visits to exhibitions and museums, cultural tours, summer camps, salons on current issues, literacy, computers, hydrotherapy, hippotherapy, gardening, horticulture, seam, activities of daily living training, social skills training. There are cases in which users integrate into the activities of the institution services as an occupational activity: kitchen, cleaning and administrative services.

Family psychoeducation

10 institutions (35.7%) mentioned having single-family psychoeducation (4 IPSSs, 2 Associations, 3 Religious Institutions, and 1 Department/Service of Psychiatry of a General Hospital; 3 from the North, 5 from the Center, 1 from the Lisbon and Tagus Valley region, and 1 from Madeira Island). 17 institutions (60.7%) mentioned having multi-family psychoeducation: 7 IPSSs, 4 Departments/Services of Psychiatry, 3 Associations, and 3 Religious Institutions; 7 from the Center, 5 from the Lisbon and Tagus Valley region, 3 from the North, 1 from Algarve, and 1 from Madeira Island.

Although it was not directly asked, 2 institutions (7.1%) mentioned providing psychoeducation for patients and 3 institutions (10.7%) mentioned to organize a mutual support group for families. Also, 1 institution stated providing training on mental health for families and/or caregivers and family mediation.

Graph 3 – Percentage of institutions providing occupational activities and family psychoeducation.



Discussion

Our survey, despite its limitation, provides important information on the current situation of psychosocial/psychiatric rehabilitation in Portugal. First of all, it is noteworthy that many institutions were unaware of some of the programs evaluated, verified by the descriptions and comments provided, which is well elucidated in the following statement which was sent by one of the institutions: "*the terms used in the survey are not part of the vocabulary of the rehabilitation entities and do not correspond to existent support programs. Terms like vocational rehabilitation, educational rehabilitation, residential rehabilitation and occupational activities are not understandable and lack clear content. The term supported education does not correspond to any known program. The questionnaire is difficult to answer because there is not a direct association to the services foreseen in the legislation*".

Non-mainstream training courses are the most common rehabilitation programs in the area of education and they are even more frequent than any program of vocational rehabilitation, a finding which is in line with the findings of Marques et al. (2006). This situation is worrying since it shows us that significant changes did not occur as a result of the Action Plan for the restructuring of mental health services (CNRSSM, 2007). Moreover, the Portuguese National Network of People with Mental Illness presented in 2006 a document created exclusively by people with lived experience of mental illness from the whole country stating their need to study in normal schools. Unfortunately, data of our survey show us that support in this direction is lacking and only 4 institutions seem to have this type of provision.

The Decree-Law 290/2009 (dated October 12, 2009) has created the *Program for Employment and Support to the Qualification of Persons with Deficiencies and*

Disabilities, where people with mental illness can be included. Although this legislation provides for training activities either integrated in the context of the actions for the general population, or through actions specifically for people with disabilities, the fact is that the later is much more common in our country. This situation can be explained, at least in part, by a funding system that encourages this type of provision, namely the concession of funding by the European Social Fund under the measure for Qualification of Persons with Deficiencies or Disabilities of the Human Potential Operational Program (Order n. º 3530/2010, dated February 25, 2010). Obviously, the legislation states that non-mainstream courses are designed for people with disabilities that do not meet the necessary conditions to integrate into education settings for the general population. However, our professional experience in the field leads us to anecdotally understand that many people with mental illness participate in non-mainstream courses, not because they do not have the skills needed to attend mainstream courses, but because they do not receive the necessary support and encouragement. Moreover, the population of people with disabilities is very heterogeneous and if we understand that non-mainstream courses might be a suitable alternative for some sub-groups of people with disabilities, evidence suggests that people with severe mental illness can attend education programs in integrated settings in the community (Rogers, Kash-MacDonald, Bruker, & Maru, 2010).

Regarding vocational rehabilitation, we consider that the low frequency of sheltered work might be considered somehow positive, since it has been demonstrated to be a segregated and institutional model (Leff & Warner, 2006). However, the fact that less than one third of the institutions assessed provide supported employment when the schizophrenia patient outcomes research team (PORT) for psychosocial treatments recommends that any person with schizophrenia aiming to work should be offered supported employment, especially IPS (Dixon et al., 2010), is disappointing. Also, the fact that no institution provides individual placement and support and the clear unawareness of professionals about this program (verified in the descriptions provided) is dramatic. Indeed, this survey allowed us to understand that in many institutions professionals are failing to keep up to date with the international literature. Moreover, institutions base their practice in the Portuguese legislation which does not provide for IPS. Although our legislation on employment for people with deficiencies and disabilities is quite recent (Decree-Law n.º 290/2009, dated October 12, 2009), it presents significant weaknesses, namely the failure to follow recent advances reported internationally and to tailor programs for the different subgroups under the general group of people with disabilities, which can explain why IPS is not included in the legislation. Although a painstaking analysis of the legislation is out of the purview of this work, we can highlight the following flaws (at least for our population): time-limited technical support to help people with disabilities in keeping the job obtained; a broad and quite confusing definition of supported employment that puts internships, socially useful activities, sheltered work centers, and placement in enclaves under the same umbrella of supported employment.

The National Commission for the Restructuring of Mental Health Services mentioned in its report (Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental, CNRSSM, 2007) the support for independent living as one of the Action Plan goals, arguing that it is referred by user and families organizations as the most suitable solution. The Action Plan (CNRSSM, 2007) pointed out the need for negotiations with the National Institute of Housing and the Local Authorities for provision of housing with a lower rent, and that this type of provision should be combined with domiciliary care services of the National Network for Continuing and

Integrated Care in Mental Health. The law of the National Network for Continuing and Integrated Care in Mental Health was enacted in 2010 (Decree Law n.º 8/2010, dated January 28, 2010) but did not include supported housing services. The law foresees, like the previous Joint Order n.º 407/98 (dated June 18, 1998), temporary group homes (for people who do not have appropriate family or social support) with support of different intensities according to the level of autonomy of the persons who live in, and socio-occupational units. The Decree-Law n.º 8/2010 innovates in relation to the Joint Order n.º 407/98 in the creation of domiciliary care specific for people with mental illness. Despite being undoubtedly a valuable service for individuals (and their families) who already have a home, the problem of homelessness or unnecessary institutionalization of the group who do not have a housing solution remains to be solved (Teixeira, Santos, & Abreu, in press). So, a program which supports people with mental illness accessing and keeping an independent house of their choice in the normal housing market is still lacking in the Portuguese legislation, which can explain why less than one quarter of our sample have this type of provision.

It is noteworthy, however, that although the legislation provides for temporary solutions, some of the institutions evaluated in our study have permanent group homes. This is a positive finding, since transitional programs lead to a chronic dislocation (Carling, 1992) and seem not improving the likelihood of independent housing (Rogers et al., 2009). Nevertheless, all housing programs provided are group living solutions when it seems that people with mental illness prefer not living with other people with psychiatric issues (Tanzman, 1993).

Moreover, the existence of group homes, permanent and transitional, within the institutions that provide services is somehow deterrent of social inclusion. This situation is more typically found in Religious Institutions, which for a long time provided asylum-type services and whose buildings are associated by the general population to the provision of psychiatric care. Therefore, group homes within the grounds of these institutions, although being a preferable solution than a psychiatric ward, can be stigmatizing.

The percentage of institutions providing occupational activities services is strikingly positive (92.9%). On the one hand, this can be due to the fact of the possibility of funding for social-occupational forums through the Joint Order n.º 407/98 and more recently for socio-occupational units through the Decree-Law n.º 8/2010. On the other hand, the study of Marques et al. (2006) demonstrated that people with mental illness believe more than professionals that competitive employment is attainable. These lower expectations of professionals about the possibility of work of people with mental illness, also demonstrated in the international literature (Rinaldi et al., 2008), can lead to more efforts to the development of less demanding activities. Although occupational activities and leisure time are an essential part of the spectrum of the rehabilitation process, it should function as such and not as a replacement of education and employment.

Finally, the results of family psychoeducation, namely the multi-family type, although still insufficient, are encouraging.

Our study has some limitations. First of all, we had a response rate of 40%, so that we cannot assure that our sample is representative of the Portuguese scenario. However, we cautiously infer that institutions developing rehabilitation programs were more likely to participate. The fact that Portuguese Departments and Services of Psychiatry of General Hospitals are more focused on treatment services can explain why we received responses from only 6 of these institutions. Secondly, although we asked if the institutions provided certain types of programs, we did not collect information regarding how many users received those programs. Finally, family psychoeducation would need better characterization, namely whether the relative with mental illness is present or not in the sessions, and the setting in which psychoeducation takes places (at the family's home or in mental health settings).

We conclude that, after six years since the publication of an Action Plan to restructure mental health services (Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental, 2007), psychiatric rehabilitation services are still poorly developed in Portugal. Due to funding reasons, institutions base their practice on the orientations foreseen in the Portuguese legislation, which, in turn, is failing to follow international guidelines.

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Capítulo 2

Psychosocial Rehabilitation for people with schizophrenia spectrum disorders in the Central region of Portugal: An exploratory study

Abstract

Portugal is attempting to change the paradigm in mental health care, which encompasses the closure of psychiatric hospitals and the development of psychosocial rehabilitation programmes. However, the evaluation of these programmes is not routinely done, which may compromise the quality of care.

We carried out a cross-sectional study to explore differences in symptomatology, global functioning, social and occupational functioning, quality of life and self-concept in a sample of 54 persons with schizophrenia spectrum disorders attending one of two psychosocial rehabilitation programmes (vocational training and occupational activities) or not participating in any psychosocial intervention.

The groups differed significantly in terms of both measures of functioning. People in vocational training demonstrated significantly higher levels of global functioning (M=59.83±11.79) than people in occupational activities (M=49.36±11.91) and than people with no activity (M=48.00±10.51), but no significant differences were found between the latter two groups. Individuals in training showed higher scores in social and occupational functioning (M=60.33±11.70) than those in occupational activities (M=50.00±12.11), although significant differences were not found between training participants and individuals with no activity (M=52.60±10.46), neither between occupational activities and no programme. Differences in quality of life were not detected.

Psychosocial rehabilitation programmes may be associated with improvement in functioning, but further emphasis should be placed on the fulfilment of personal goals and the achievement of a meaningful life, which might impact quality of life outcomes.

Confirmation of these findings in prospective studies is crucial. Although steps are being taken towards implementing rehabilitation, recovery-oriented services (and not only targeting functioning) may merit consideration by the National Commission for the Restructuring of Mental Health Services.

Key-words: psychosocial rehabilitation; schizophrenia; recovery

Introduction

A programme of deinstitutionalisation and restructuring of mental health services, emphasising psychosocial rehabilitation development, has been implemented in Portugal since 2007 [National Commission for the Restructuring of Mental Health Services in Portugal (Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental em Portugal, CNRSSMP), 2007]. The World Health Organization (WHO, 2001) defines psychosocial rehabilitation as “a process that offers the opportunity for individuals who are impaired, disabled or handicapped by a mental disorder to reach their optimal level of independent functioning in the community” (p. 62). However, Farkas and Anthony (2010) go beyond functioning and suggest that an important aspect of rehabilitation is the improvement of role performance in a chosen environment within the overall mission of recovery or the regaining of a meaningful life.

Although studies conducted abroad have demonstrated the cost-effectiveness (Barton, 1999) and the effectiveness of an array of psychosocial interventions, which impact outcomes related to psychosocial functioning and psychopathology (Mueser, Deavers, Penn, & Cassisi, 2013), the field of rehabilitation in Portugal is failing to implement recent advances. In the Central region of our country the common practices are prevocational training, i.e, preparatory activities before entering into competitive employment (Crowther, Marshall, Bond, Huxley, 2001), and occupational therapy, which encompasses the performance of mental or physical activities aiming at influencing wellbeing, improving skills, increasing the level of functional independence and developing a sense of competency and mastery with the ultimate goal of hasten recovery (Reed & Sanderson, 1999). However, data concerning their effectiveness are absent, explained by the fact that only a small proportion of the institutions that provide psychosocial rehabilitation interventions are involved in research projects (CNRSSMP, 2007). Furthermore, the 2010 Activity Report of the Team of the Project for Continuing and Integrated Care in Mental Health (Equipa de Projecto de Cuidados Continuados Integrados de Saúde Mental, n.d.) states that, in our country, monitoring of quality was not part of mental health services' routine in the last years, which is deemed to prevent their improvement.

Taking into account this reality, we carried out an exploratory study to assess symptomatology, global functioning, social and occupational functioning, quality of life and self-concept of people with schizophrenia spectrum disorders attending vocational training or occupational activities and of a group of users with the same diagnoses not participating in any psychosocial programme. Differences between groups were assessed.

Methods

Study design and procedure

The study had a cross-sectional design with a sample of 54 users. Data collection was carried out in four institutions: two social solidarity institutions (n=11; n=13) and two psychiatric hospitals (n=21; n=10) in Coimbra district. In each centre, staff members were asked to identify people with severe mental illness who were willing to participate in the study. After full information on the study was given, all users gave their informed consent for participation. The study was approved by the ethical board of the four sites and by the National Commission for Data Protection (permission n.º 3127/2010).

Users were eligible if all the following conditions were present: 1) being at least 18 years old, 2) having a diagnosis of a schizophrenia spectrum disorder (e.g. schizophrenia, bipolar disorder, schizoaffective disorder) as determined by the information contained in their clinical records, 3) attending regularly appointments with a psychiatrist, and 4) being under medication. Patients with severe cognitive deficits that did not enable them to understand the questions of the different scales and questionnaires were excluded, as well as patients with diagnosed mental retardation or dementia.

Participants meeting the inclusion criteria of our study were either attending vocational training (n=30), occupational activities (n=14) or were part of a control group of unemployed users who were not attending any type of psychosocial intervention (n=10).

Vocational training in this study means non mainstream classes (in mental health settings) for people with mental illness (and sometimes along with other disability groups) as a preparatory step for entering the mainstream labour market. Examples of occupational activities are handicrafts, painting, gardening, weaving, pottery, which are performed in mental health settings with the aim of helping people gain or regain abilities.

Data collection was conducted from October 2010 to April 2011. The first author, who has training in clinical psychology, carried out an interview with all the participants, focusing on: current problems; medical history; current treatment and rehabilitation modality; educational and work history; source of income; current housing situation; current and past relationships with family and significant others; and hobbies. This interview was carried out taking into account the principles of alliance building, empathy, non-judgmental approach and unconditional acceptance. The interviewer identified potential solutions for current problems.

All the measures described below were collected during this interview, including questions of the *Brief Psychiatric Rating Scale* and all the self-reported questionnaires.

Besides, the first author met with the staff of each of the centres to discuss the individuals assessed, in order to facilitate scoring of rating scales.

Measures

Brief Psychiatric Rating Scale – expanded version

Psychopathology was assessed with the 24 item version of the Brief Psychiatric Rating Scale (BPRS; Ventura et al., 1993) adapted by Gusmão, Talina, Xavier and Caldas de Almeida (1996). Items of the BPRS are rated on a 1 to 7 point scale, where the higher the score, the more severe is the symptom. The rating of the items was based on patient behaviour and reports during the interview, as well as on discussion with the staff of the mental health centre where the assessment took place.

Global Assessment of Functioning

The Global Assessment of Functioning (GAF) scale (American Psychiatric Association [APA], 2002) was used to assess current global functioning. GAF reflects the clinician rating of the patient’s functioning on a scale ranging from 0 to 100 where the higher the score, the better is the functioning. The scale is divided into ten levels of functioning, each of which comprises two components: 1) symptoms severity and 2) functioning. Hilsenroth and colleagues (2000) reported high levels of inter-rater reliability (ICC= 0.86) and validity. GAF was rated after the research interview and discussion with the staff of the institution and was based on the level of functioning of patients at the time of evaluation.

Social and Occupational Functioning Assessment Scale

Problems in social and occupational functioning were assessed with the Social and Occupational Functioning Assessment Scale (SOFAS) proposed by DSM-IV-TR (APA, 2002). This scale differs from GAF by the fact of exclusively assessing the individual level of social and occupational functioning, not depending directly on the global severity of their psychiatric symptoms. While GAF does not take into consideration deficits in functioning due to physical limitations, SOFAS considers any impairment of the social and occupation activity due to mental and physical health problems. According to Hilsenroth et al. (2000) SOFAS is a valid measure of problems in social, occupational, and interpersonal functioning and can be reliably scored (ICC = 0.89).

World Health Organisation Quality of Life Assessment –Brief Form

The participants filled in the brief version of the World Health Organisation Quality of Life assessment (WHOQOL-BREF) validated in Portugal by Vaz Serra et al. (2006). The WHOQOL-BREF consists of 26 items and is organised in four domains: Physical, Psychological, Social Relationships and Environment. Vaz Serra et al. (2006) reported that the instrument demonstrated good indices of internal consistency (α = 0.79

when analysing the four domains; α = 0.92 when analysing the 26 items; it ranged from 0.64 to 0.87 when considering each domain individually), test-retest stability (Pearson correlation coefficients ranged from 0.65 to 0.85) and discriminant and construct validity.

Inventário Clínico do Auto-Conceito (*Self-Concept Clinical Inventory*, Vaz Serra, 1986)

The Self-Concept Clinical Inventory is a scale to assess the emotional and social aspects of social-concept. It is constituted by 20 questions requiring responses ranging in a scale from 1 to 5 (from “Disagree” to “Totally agree”) where the higher the score, the better is the individual’s self-concept. It assesses stable personality characteristics and not transient states. The factors that constitute the scale are: Acceptance/ Social Rejection; Self-Efficacy; Psychological Maturity; Impulsivity/Activity. Vaz Serra (1986) reported good internal consistency (Spearman-Brown coefficient was 0.791) and test retest reliability (r = 0 .838).

Data analysis

IBM SPSS Statistics 20 was used for descriptive and inferential statistical analysis.

One Way ANOVA (and Bonferroni post-hoc test) was used to determine the existence of significant differences between the three groups (vocational training, occupational activities, and no psychosocial activity). An equivalent non-parametric test (Kruskal Wallis) was used when the Shapiro-Wilk test demonstrated absence of normal distribution (or when values of skewness and kurtosis were not between -1>1) and/or when Levene's test did not show homogeneity of variances. Chi-square was used for comparison of nominal variables.

We used 0.05 for alpha in the comparisons between groups and 0.01 for diagnostic tests.

In the cases where Kruskal Wallis was used, post-hoc analyses were done using Mann-Whitney tests with Bonferroni correction. For Bonferroni adjustment we divided the p value to be achieved for significance (0.05) by the number of paired comparisons to be made. Therefore, when analysing the three groups, any pair had to achieve a significant value smaller than 0.017 (0.05/3) to be significant at the 0.05 level of probability.

Univariate ANCOVAs were run to control for differences in the variable age between the three groups. The assumptions underlying the analysis of covariance were tested: for normality, linearity, homogeneity of regression slopes and homogeneity of variance. The skewness and kurtosis of both dependent variables and concomitant variable were considered to satisfy the assumption of normality when values were between -1.0 and + 1.0. The assumption of homogeneity of regression slopes was verified by the test of an interaction term composed of the factor and covariate ($p > 0.01$) and the results of the Levene test supported the homogeneity of variance when $p > 0.01$. When comparing adjusted means, we used Bonferroni correction to protect against inflating a Type I error rate.

Before conducting correlation tests, the presence of a linear relationship and the normality of distribution were tested. When the assumptions were met we used the Pearson correlation. In the remaining cases, Spearman's correlation test was run. We classified correlation values < 0.5 as weak; 0.5 – 0.79 as moderate; > 0.8 as strong.

Results

Socio-demographics characteristics of the sample can be found in table 1. No statistically significant differences between the three groups were found as regards gender, education, marital status, and diagnosed psychosis. Differences in the variable age were detected ($F(2, 51) = 9.50$, $p < 0.001$). Individuals in training were significantly younger than both individuals in occupational activities ($p = 0.031$) and individuals not participating in any programme ($p = 0.001$). No differences in the variable age were found between the latter two groups ($p = 0.419$).

Housing situation was different across groups (χ^2 (6, $N = 54$) = 14.76, $p = 0.022$). It is noteworthy that 71.4% of people in occupational activities lived in staffed residences and 80% of people with no formal activity lived with their family or partner. People in training were equally distributed in staffed residences and family homes (36.7% in each of these groups).

The ANOVA showed no differences in the global score of the BPRS ($F(2, 51) =$ 1.85 , $p = 0.168$). However, when the items of the BPRS were analysed individually, the Kruskal Wallis test demonstrated significant differences in the following subscales: *Self-neglect* (χ^2 (2, $N = 54$) = 7.68, $p = 0.022$), *Motor retardation* ($\chi 2$ (2, $N = 54$) = 6.41, $p = 0.041$) and *Distractibility* ($\chi 2$ (2, $N = 54$) = 8.99, p = 0.011).

Taking into consideration Bonferroni correction, post-hoc analyses showed that people not attending any activity presented more self-neglect than those in training [$U =$ 84, $p = 0.016$ (two-tailed)]. No differences were found between individuals not participating in any programme and occupational activities subjects [$U = 63$, $p = 0.728$ (two-tailed)], neither between training participants and occupational activities participants [$U = 134$, $p = 0.033$ (two-tailed)] (note: alpha set for significance was

0.017). However, when we analysed *Self-Neglect* (Skewness = 1.26) controlled for age we could not reject the null hypothesis of equality of means across the three groups ($F(2, 50) = 1.931$, $p = 0.156$, partial eta squared = 0.072).

Individuals in training showed lower scores of *motor retardation* than individuals in occupational activities [$U = 126.5$, $p = 0.016$ (two-tailed)] but no differences were found between training participants and individuals with no activity [$U = 115.5$, $p = 0.203$ (two-tailed)]. Mean ranks of the scores in *motor retardation* of participants in occupational activities and participants in no programme were not statistically different [$U = 48$, $p = 0.184$ (two-tailed)]. Lack of homogeneity of variance of the variable *Motor Retardation* verified by Levene's Test ($p = 0.007$) and by a ratio of largest group variance to smallest group variance of 4.63 did not allow us to control for age.

Individuals in training demonstrated lower levels of *Distractibility* than subjects in the group comprising individuals with no activity [$U = 81$, $p = 0.006$ (two-tailed)]. No differences in *Distractibility* scores were found between participants in training and subjects in occupational activities [$U = 142.5$, $p = 0.025$ (two-tailed)], neither between occupational activities and no activity [$U = 67.5$, $p = 0.858$ (two-tailed)]. It was not possible to verify the differences between groups in the variable *Distractibility* adjusted for age since the assumptions of homogeneity of the regression slopes ($p = 0.010$) and homogeneity of variance ($p < 0.001$) were not met.

A Spearman's correlation was run to determine the relationship between *Motor Retardation* and age, and between *Distractibility* and age. It demonstrated a weak, positive monotonic correlation between *Motor Retardation* and age ($r_s = 0.39$, n = 54, $p = 0.003$) and a weak, positive monotonic correlation between *Distractibility* and age ($r_s = 0.40$, n = 54, $p = 0.003$). Spearman’s test demonstrated the absence of correlation between *Motor Retardation* and *Distractibility* ($r_s = 0.25$, n = 54, $p = 0.065$).

As shown in table 2, significant differences between groups were found in global functioning (*F*(2, 51) = 6.07, *p* = 0.004). Post-hoc analysis showed that people in vocational training functioned better than people in the other two groups (*p* = 0.022 in the two comparisons), although no differences were found between occupational activities and no rehabilitation activity (*p* = 1.000). Univariate ANCOVA also demonstrated that the main effect for GAF by programme remained statistically significant (F (2, 50) = 6.229, *p* = 0.004, partial eta squared = 0.199) when means are adjusted by age. Participants in training presented higher levels in GAF scores compared to participants in occupational activities (M = 60.67, SE =2.27 vs M= 48.75, SE=2.27; *p* = 0.014) and participants who do not participate in any programme (M = 60.67, SE =2.27 vs M = 46.35, SE = 4.00; *p* = 0.015). The comparison of the difference between occupational activities and no programme was not statistically significant (*p* = 1.000).

A significant effect of intervention group on SOFAS was verified by ANOVA (*F*(2, 51) = 4.389, *p* = 0.017). Individuals in training showed higher scores in SOFAS than those in occupational activities (*p* = 0.024) but no differences were found between training participants and individuals with no activity (*p* = 0.221), neither between occupational activities and no programme (*p* = 1.000). After adjusting for age, the significant difference was maintained (F (2, 50) = 6.309, *p* = 0.004, partial eta squared = 0.202). Individuals in training demonstrated higher scores in SOFAS than those in occupational activities (M = 61.80, SE = 2.21 vs M = 48.93, SE = 3.08; *p* = 0.005), but did not show significantly different scores (note that we used an adjusted alpha to protect against Type 1 error) from subjects not participating in any programme (M = 61.80, SE= 2.21 vs M = 49.69, SE = 3.91; *p* = 0.042). The comparison of the difference between occupational activities and no programme was not statistically significant (p = 1.000).

A statistically significant difference between groups was also found in the variable *Psychological Maturity* ($F(2, 51) = 4.10$, p = 0.022), which assesses characteristics like assertiveness, responsibility and tolerance. Post-hoc analysis showed that people in vocational training showed higher levels of *Psychological Maturity* than people in occupational activities (p = 0.022). However, differences between vocational training and no activity (p = 0.502), as well as between no activity and occupational activities (p = 1.000) were not found.

Despite ANOVA results showing significant differences in the physical and social relationship domains of quality of life and a p value in general self-concept on the threshold of significance, these were not confirmed through post-hoc analysis.

There was a positive and weak correlation between General Quality of Life and GAF scores [r (52) = 0.43, p = 0.001], as well as between General Quality of Life and SOFAS [r (52) = 0.30, p = 0.025]. GAF and General Self-Concept were demonstrated to have a weak and positive correlation [r (52) = 0.31, p = 0.023] as well as SOFAS and Self-Concept [r (52) = 0.35, p = 0.01]. General Quality of Life was positively and moderately correlated with General Self-Concept [r (52) = 0.50, p <0.001].

Table 1. Socio-demographic characteristics and clinical diagnoses in the overall sample and the three assessed subgroups.

Variable	**Overall group N= 54 (Mean±SD/ Frequency)**	**Occupational activities N=14 (25.9%) (Mean±SD/ Frequency)**	**Vocational training N=30 (55.6%) (Mean±SD/ Frequency)**	**No rehabilitation activity and unemployed N=10 (18.5%) (Mean±SD/ Frequency)**	***p****
Age	41.4 ± 11.5	45.1±9.5	36.4 ±7.9	51.3±15.4	0.000
Male	37 (68.5%)	11 (78.6%)	21 (70.0%)	5 (50.0%)	0.320
Education					
Basic Education or less	37 (68.5%)	12 (85.7%)	18 (60.0%)	7 (70.0%)	0.511
Secondary Education	12 (22.2%)	1 (7.1%)	9 (30.0%)	2 (20.0%)	
University attendance	5 (9.3)	1 (7.1%)	3 (10.0%)	1 (10.0%)	
Marital status					
Single	36 (66.7%)	10 (71.4%)	21 (70.0%)	5 (50.0%)	0.223
Married/with a partner	7 (13.0%)	1 (7.1%)	3 (10.0%)	3 (30.0%)	
Divorced	10 (18.5%)	3 (21.4%)	6 (20.0%)	1 (10.0%)	
Widower	1 (1.9%)	0	0	1 (10.0%)	
Housing situation					
Staffed residences	23 (42.6%)	10 (71.4%)	11 (36.7%)	2 (20.0%)	0.022
Institutionalisation for forensic issues	5 (9.3%)	0	5 (16.7%)	0	
Lives with family or partner	23 (42.6%)	4 (28.6%)	11 (36.7%)	8 (80.0%)	
Lives alone with family support	3 (5.6%)	0	3 (10.0%)	0	
Diagnosis					
Schizophrenia	32 (59.3%)	9 (64.3%)	20 (66.7%)	3 (30.0%)	0.140
Bipolar Disorder	13 (24.1%)	3 (21.4%)	4 (13.3%)	6 (60.0%)	
Schizoaffective disorder	3 (5.6%)	1 (7.1%)	2 (6.7%)	0	
Psychosis (not specified)	6 (11.1%)	1 (7.1%)	4 (13.3%)	1 (10.0%)	

Note: * *p* value refers to overall differences between the three groups. Post-hoc comparisons are presented in the results section.

Table 2. Measures of global, social and occupational functioning, quality of life and self-concept in the overall sample and the three assessed subgroups.

Variable	**Overall group N= 54 (Mean±SD/)**	**Occupational activities N=14 (Mean±SD/)**	**Vocational training N=30 (Mean±SD/)**	**No rehabilitation activity and unemployed N=10 (Mean±SD/)**	***p****
Global score BPRS	45.20±13.21	49.29±14.66	42.17±11.91	48.60±13.79	0.168
GAF	54.93±12.67	49.36±11.91	59.83±11.79	48.00±10.51	0.004
SOFAS	56.22±12.32	50.00±12.11	60.33±11.70	52.60±10.46	0.017
General Quality of Life	60.65±19.64	58.04±13.52	64.58±21.30	52.50±20.24	0.207
Quality of Life: Physical Domain	62.30±16.47	57.65± 13.20	67.14±16.89	54.29±15.59	0.045
Quality of Life: Psychological Domain	62.35±17.38	59.23±15.69	65.69±17.73	56.67±17.92	0.273
Quality of Life: Social Relationships	61.57±22.51	53.57±15.92	68.33±20.69	52.50±29.93	0.044
Quality of Life: Environment	58.80±15.48	56.03±11.66	62.71±15.59	50.94±17.31	0.082
General Self-Concept	69.24±11.23	64.29±8.62	72.50±11.23	66.40±12.14	0.050
Acceptance/ Social Rejection	16.63±4.05	14.79±3.12	17.47±3.74	16.70±5.46	0.122
Self-Efficacy	19.63±4.50	18.64±3.88	20.87±4.57	17.30±4.24	0.058
Psychological Maturity	14.24±2.55	12.86±2.11	15.03±2.59	13.80±2.20	0.022
Impulsivity/Activity	10.83±2.46	9.93±1.94	11.50±2.45	10.10±2.72	0.080

Note: * *p* value refers to overall differences between the three groups. Post-hoc comparisons are presented in the results section.

Discussion

Lack of scientific data on psychosocial rehabilitation in Portugal is a reality that may affect the quality of services provided. Taking into account the absence of research, we started with carrying out an exploratory study. We examined functioning (global, social and occupational), quality of life and self-concept of people with schizophrenia spectrum disorders attending vocational training, occupational activities and in no formal activity. The groups were equivalent in terms of gender, education, marital status and diagnosis. We verified that people in training presented higher levels of global functioning than people in the other two groups. This is a cross-sectional study, so that causality cannot be inferred. It might be that people entered into vocational training because they functioned better *a priori*. Moreover, we could hypothesize that people in training show higher levels of functioning because they are younger. However, when age is held constant, this finding was maintained. Nevertheless, we assume that controlling a variable that is significantly different across groups, as was the case with age, might not be appropriate (Miller and Chapman, 2001), so that the analysis of covariance should be treated with caution. In fact, it is highly likely that it is not by chance that people in vocational training are younger than people in the other groups, so that removing variance associated with age might not be suitable.

Individuals in training showed higher scores in Social and Occupational Functioning than individuals in occupational activities but surprisingly no differences were found between training participants and individuals with no activity. This may be due to small sample size and therefore lack of power to detect significant differences or due to the fact that 80% of people with no formal activity live with family or partner, while just 28.6% of individuals in occupational activities live with family or partner and

46.7% of training participants live with family, partner or alone. It is likely that living with family or partner play a significant role in social functioning. Moreover, *Psychological Maturity* was found to be equal between training participants and individuals with no activity, which may affect scores in social functioning.

Occupational therapy services involve "developing, improving, or restoring daily living skills, work readiness or work performance, play skills or leisure capacities, or enhancing educational performance" (Reed & Sanderson, 1999, p.7), so that one could expect to find differences between people in occupational activities and people with no activity in terms of the two measures of functioning. First of all, people who do not perform a formal activity might in fact have activities outside mental health services, which can also be therapeutic. Secondly, and although in theory occupational activities must be meaningful and purposeful to individuals (Reed & Sanderson, 1999), future research is needed to assess to what extent people in this programme are in fact motivated to perform these activities or are simply doing what they are offered. On the other hand, since vocational training has the specific target of including people with mental illness in the labour market, it is possible that participants in this programme may have higher expectations of working than people in occupational activities, which might moderate different levels of commitment to the programmes. In fact, when examining vocational rehabilitation, Rosenfield (1992) verified that it was the hope or expectation of working that was critical to individuals receiving services.

Although differences in global, social and occupational functioning were detected between groups, measures of quality of life and self-concept (with exception of *Psychological Maturity*) were equal across the three groups. This finding is to some extent consistent with the work of Edmondson, Pahwa, Lee, Hoe, and Brekke (2012) who found that satisfaction with social relationships did not improve as social functioning improve in a sample of 145 individuals with schizophrenia. Likewise, better global, social and occupational functioning in people in vocational training is not accompanied by better quality of life. In fact, correlations between *General Quality of Life* and both measures of functioning were weak. This finding supports the idea that rehabilitation in the institutions studied may be lacking a recovery orientation, since although an association with functioning seems to exist, the perception of a fulfilling life is probably not being reached (Farkas & Anthony, 2010). It is therefore important that rehabilitation services extend their remit beyond functioning to supporting individuals in building a life project with meaningful roles in society.

According to the National Commission for the Restructuring of Mental Health Services (2007), rehabilitation aims to enable the person with disability to achieve the highest level of personal, social and professional functioning, in the least possible restrictive environment. Professional training in mental health settings cannot be considered a non-restrictive environment. Moreover, according to Hansson (2006), reducing stigma is an important variable for quality of life and is a crucial aspect to consider in service interventions. The absence of an improved quality of life of people in training can be due to the stigma attached to courses in mental health settings.

On the other hand, personality factors like mastery and self-efficacy are mediators of changes in subjective quality of life (Hansson, 2006) and, in fact, our sample did not show differences in general self-concept and self-efficacy.

Despite the methodological limitations of comparisons between studies, when we set our results side by side with the findings of Vaz Serra, Pereira and Leitão (2010) who measured quality of life with the same instrument (WHOQoL-Bref, Portuguese version) in a sample of 133 persons with schizophrenia (37 institutionalised for many years in a psychiatric hospital, 25 outpatients, and 71 temporarily hospitalised for acute crisis), we find that our group in vocational training has higher scores in almost all domains of quality of life than outpatients and better quality of life in all facets than institutionalised and hospitalised individuals, which shows us that important advances are being made in the care provided to people with severe mental illness. However, results of individuals receiving occupational activities are not so encouraging, since their scores are lower than those of outpatients in all facets. When comparing occupational activities with institutionalisation we observe a slightly higher score in general quality of life in the former (58.04 vs 55.41) as well as in the environment and psychological domains.

Our investigation has a number of limitations: small sample size; the impossibility of inferring causality as a consequence of its cross-sectional design; and a possible selection bias, since some of eligible users refused to participate in our study (and we were not given their exact number).

In spite of its limitations, this study may have important implications for research and mental health practice in Portugal. It is a first step in the quest for the assessment of quality of services and the outcomes of people for whom they are created. If we are to develop programmes that aim not only to achieve an improvement in functioning, but also in quality of life, maybe the time has come to rethink our practices. We are still providing traditional vocational approaches, which research has shown are not effective (Bond, 1998). Evidence-based interventions outside mental health services should be developed, such as Individual Placement and Support and Supported Education, in order to combat stigma and facilitate social inclusion. However, we recognise that some persons with mental illness might benefit from occupational therapy, but whenever possible this should not substitute other services but rather complement them.

Future directions include carrying out longitudinal randomised controlled studies that can allow a better control of individual differences and the observation of the evolution of the assessed variables. Since the objective of vocational training is to help people with mental illness to achieve a job in the competitive labour market, an important outcome to assess in future studies is the number of people who completed the course and gained employment in a mainstream job.

Conclusion

Our findings comprising cross-sectional data of people with schizophrenia spectrum disorders receiving care in the Central region of Portugal suggest that individuals in vocational training have higher levels of global functioning than those in occupational activities or with no activity. Training participants also show better social and occupational functioning than people in occupational activities. However, quality of life and almost all self-concept domains appear not to differ across groups. Longitudinal studies are warranted to better understand these findings and assess the possible existence of a cause-effect relationship between programmes and results.

A holistic approach to persons with severe mental illness is one of the currently unmet goals of psychiatric rehabilitation in our region. Therefore, it is vital that the National Commission for the Restructuring of Mental Health Services in Portugal drive efforts towards the development of recovery-oriented services, that is, services tailored according to the preferences, values, needs and personal aspirations of people with mental illness, thereby targeting subjective quality of life outcomes.

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Capítulo 3

Psychiatric rehabilitation and social inclusion of people with mental illness: A Portuguese experience and a critical analysis of current barriers[2]

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Abstract

The delivery of psychiatric rehabilitation interventions has been recognised as fundamental to facilitate recovery of people with severe mental illness. Although Portugal has developed a plan to restructure mental health services between 2007-2016, multiple barriers are hindering its effective implementation. We aim to describe a Portuguese psychiatric rehabilitation institution and analyse barriers in the mental health paradigm change. With our experience, we intend to help countries that are planning or passing through a change of paradigm in mental health care to anticipate and avoid similar obstacles. Sources used were research literature, government policy documents and legislation, *in loco* experience and experiential knowledge. The case study was carried out using interactive (participant observation and non-structured interviews) and non-interactive techniques (document analysis, namely the target institution reports, projects and dossiers). Barriers found include not complying with the most recent available evidence and the use of outdated and non evidence and values-based models. Moreover, a deficient monitoring and evaluation of services' quality, resistance to change, lack of appropriate training of professionals, lack of involvement of users in their care planning and funding issues are also contributors for the perpetuation of this scenario.

Key-words: severe mental illness; psychiatric rehabilitation; recovery; social inclusion

Introduction

The change of paradigm in psychiatry, which implies the creation of services for the social inclusion of people with severe mental illness, has been a difficult process in Portugal. Indeed, according to the updating of the Mental Health National Plan (Ministério da Sáude, 2012), strong barriers to the progress of mental health care remain to be solved, namely the existence of a funding system which encourages institutional practices rather than community care.

The main goals of this article are to describe a psychiatric rehabilitation institution and to analyse barriers in the mental health paradigm change in Portugal. The sources used were research literature, government policy documents and legislation, *in loco* experience and experiential knowledge. The case study was carried out using interactive techniques (participant observation and non-structured interviews) and non-interactive techniques (document analysis, namely the institution reports, projects and dossiers). Participant observation was carried out by the first author, who accompanied the psychologist of the institution in all her daily tasks firstly during one whole week and in a second phase on a monthly basis for 6 months. The aim of participant observation was to understand the routine of the institution, the roles and tasks of the different professionals (mainly the technical team which was composed of one psychologist and two social workers), and the explicit and implicit rules of the institution. The interviews were conducted with the psychologist of the institution and addressed the following topics: programmes developed by the institution, their objectives, addressees and eligibility, and activities within each programme. We aimed to provide a global perspective of the study object and, based on the analytical knowledge achieved, to develop questions for future research. In order to provide a basis for our analysis, a brief review of psychiatric rehabilitation interventions for people with mental illness is first presented. We proceed with the description of the institution to finally compare it with what would be expected according to the state of the art. Barriers to mental health services change and recommendations to tackle them are also discussed.

The spectrum of psychiatric rehabilitation programmes

According to Farkas and Anthony (2010) psychiatric rehabilitation aims to improve performance in a valued role and chosen environment within the “real world” with the ultimate mission of enhancing recovery. The concept of recovery is defined by Anthony (1993) as a personal process leading to a meaningful life even with the catastrophic effects caused by the illness.

Since people with mental illness want more than just symptom alleviation (Anthony, 1993), psychiatric rehabilitation services developed programmes to help them to fulfil their needs in terms of housing, work and education.

There is an array of work rehabilitation programmes, varying in the setting they are provided (real or sheltered), the tasks and posts offered, and the length of the support provided. Sheltered workshops and supported employment are services aiming at providing the possibility of paid work. In a sheltered workshop, a patient with severe mental illness works with other patients, typically in factory work, such as packaging a product (Twamley, Jeste, & Lehman, 2003). This programme has lost popularity and nowadays it is considered an institutional and segregated model (Leff & Warner, 2006). Supported employment was developed by Wehman (1986) and consists in a “place-train” approach, avoiding long prevocational evaluation and training (Becker, Drake, & Naughton, 2005).

A specific model of supported employment for people with severe mental illness, the Individual Placement and Support (IPS) was developed in New Hampshire in the 1990s (Becker & Drake, 1994; Drake & Becker, 1996). IPS is an evidence-based approach characterised by the following principles (Bond, 1998; 2004): services focused on competitive employment; eligibility based on consumer choice; rapid job search; integration of rehabilitation and mental health; attention to consumer preferences; time-unlimited support; benefits counselling.

The difficulty of people with mental illness in pursuing educational goals led to the development of the supported education programme, which finds its roots in the Center for Psychiatric Rehabilitation at Boston University (Anthony & Unger, 1991; Unger, Danley, Kohn, & Hutchinson, 1987). This programme provides support to help people with mental illness access normalised post-secondary education, instead of providing education through non-mainstream programmes (Farkas & Anthony, 2010). According to Anthony and Unger (1991), classes delivered at a community mental health centre are not, by definition, supported education.

Education specialists support patients in services that enhance the likelihood of success in the achievement of the educational goal, such as choice of the programme, enrolment and financial support possibilities (Unger, Pfaltzgraf, & Nikkel, 2010). The core services can be grouped as career planning, academic survival skills, and outreach to services, which are provided for an unlimited time (Mowbray et al., 2005).

Similarly to the fields of work and education, housing facilities for people with severe mental illness also present in many forms.

The concern with housing in the community dates back to the closure of large long-stay hospitals which led to the creation in the 1960s and 1970s of “special needs” accommodation such as group homes (Bochel, Bochel, & Page, 1999). In these decades, there was a proliferation of transitional halfway houses and the concept of a residential continuum appeared (Carling, 1990).

However, the effectiveness of halfway houses in facilitating the independent functioning of people with mental illness in the community was questioned. Despite transitional residential programmes may be a preferred alternative to institutional care, Cometa, Morrison and Ziskoven (1979) concluded in their review that they fail in helping people to achieve long-term housing or community integration. Indeed, as mentioned by Carling (1992), transitional stays in residential settings can create difficulties for the individuals, namely a chronic dislocation since improvement in functioning, or even the deadline of the programme, implies a physical move and frequently a return to family, boarding home, hospital or homelessness. Moreover, Tanzman (1993) demonstrated that people with mental illness prefer to live independently and not with other people also suffering from mental illness and prefer to have flexible, outreach staff support as needed, instead of live-in staff support. All together, these factors led to the development of the supported housing model.

Supported housing is defined as a programme that provides independent housing in the community along with an array of community-based services (Rog, 2004).

According to Carling (1990) supported housing is based on three central principles: “a) consumers choosing their own living situation; b) consumers living in normal, stable housing, not in mental health programmes; c) consumers having the services and supports required to maximise their opportunities for success over time” (p. 973). Tabol, Drebing and Rosenheck (2010) upon reviewing the relevant literature identified the elements of the supported housing model which can be divided into five categories: normal housing (e.g., integrated with non-consumers), flexible support;

separation of housing and services; choice; and immediate placement (no preparatory setting).

Case Study

The institution is a not-for-profit organisation, founded in 1990. The head office and most of the activities are located within a psychiatric hospital, which is situated outside the community. There are other institutions providing psychosocial rehabilitation services in the Central region of Portugal, but we chose this one since it focuses exclusively people with severe mental illness. To our knowledge, the only institution with the same aim in the Central region of our country is located almost 150Km away. However, there are other institutions providing psychosocial services for a wider range of disability groups, such as mental retardation and dementia.

The services provided are vocational training, sheltered employment, post-placement support and sheltered housing.

Vocational Training Centre

Since 1994, the institution has developed professional training courses, having as a main objective the development of skills for the performance of a professional activity in the competitive labour market.

Trainees are adults with mental illness, women and men, aged between 16 and 45 years old. They should be followed by a psychiatrist, be clinically stable and independent in daily life activities. People with a substance abuse disorder are not eligible.

The professional training centre is situated in the institution facilities (within the psychiatric hospital) and provides 7 courses with a capacity for 58 trainees, the training period being from 1 to 4 years. The courses are: Construction, Horticulture, Cleaning, Cooking, Gardening, Computers and Graphic Design. Curricula include technical training specific to each area and additional training in Literacy, Personal Development (social skills training), Physical Education, Health and Safety at Work and Job Search Techniques. After successfully concluding the course, trainees do a one-year internship.

There is no necessary minimum qualifications to attend the courses, except Graphic Design and Computers, for which is required the 9th grade (3rd cycle of Basic Education).

Trainees are given a studentship and a subsidy for transportation and meals as well as for accommodation when living more than 50km away from the institution.

Sheltered Work Centre

The sheltered work centre is a small firm aiming to assure people with mental illness the possibility of a paid activity as well as the possibility of training and professional development that allow, whenever possible, their inclusion in the mainstream labour market.

The sheltered work centre is intended for people with chronic mental illness, women and men, of working age, who have already completed the appropriate process of medical rehabilitation. Employees in sheltered work should have sufficient autonomy in daily living activities and the ability to understand and comply with rules. In order to integrate into the sheltered work centre the person with mental illness should have a work capacity of at least one third of the one required for an employee without mental illness in the same post. Thus, sheltered jobs aim to benefit persons that have a low level of productivity. Before a contract is signed, workers pass through a phase of internship where productivity deficits are assessed in order to verify if the level presented is sufficient to integrate into the centre.

The sheltered work centre functions as a business, having economic and administrative autonomy. It covers two sectors of economic activity: the primary sector with activities of horticulture and the tertiary sector, comprising cleaning and gardening services.

Until 1998, the psychiatric hospital where the institution is situated was the only client of the sheltered work centre. However, since 1998, the centre started to provide services in the community, leading to an increase of its clients.

The centre has the capacity to employ 35 persons with mental illness. The workers earn the national minimum salary. A public employment centre funds annually the amounts corresponding to the productivity deficit. The sheltered centre, through the production, commercialisation and services sectors, ensures the remainder of the salary of the workers with mental illness, as well as the total amount of the wages of the supervisors in the field and the management costs. The centre also provides a work insurance, food and transportation for its workers with mental illness. Finally, it is important to note that if the worker with mental illness demonstrates the ability to integrate into the normal market and there is that possibility, the user is transferred. The sheltered centre is always the last job alternative.

Post-Placement Support

This programme provides continuous support after placement in the regular labour market. The recipients are people with mental illness, aged between 16 and 55 years old. The programme has a capacity for 12 persons who are distributed among different activities, such as farming, construction, clerical services and cleaning.

In the process of placement, staff members always take into account the preferences of the users and their work experience. It is noteworthy that the post-placement support programme is intimately linked to the vocational training centre. This means that all the users must complete satisfactorily a vocational training course in order to be admitted in the post-placement support programme.

Before placement, the programme team goes to the workplace in order to check its hygiene and safety conditions. After placement, members of staff assess if the user is satisfied with the job and assist him/her in overcoming social, psychological and professional difficulties, including support in solving problems related to Social Security benefits. The rehabilitation team is always available to travel to the workplace in order to solve any problem that may arise. Also, post-placement support personnel work directly with employers in order to explain to them the difficulties of the users, stressing their strengths and weaknesses. The diagnosis is never disclosed and employers only receive the information that the person suffers from mental illness. Staff members negotiate with employers, so that provision of more guidance and flexibility in work hours (in order that the users can attend their healthcare appointments) are obtained. It is noteworthy that post-placement programme staff accompany patients to their appointments with the psychiatrist, which promotes coordination between vocational rehabilitation and treatment services.

There are regular meetings between the rehabilitation team and the employer in order to discuss the performance and progress of the user. Programme staff interview the employer to gather information about satisfaction with the worker (for example, whether the worker complies with his/her duties, if he is punctual and hardworking and if he/she has a satisfactory relationship with colleagues) and intervene if necessary. The family is also contacted frequently.

Although the programme was initially conceived for one year, rehabilitation team supports users regularly for 3 years. Despite support being gradually withdrawn, in order to reinforce autonomy, it is, to some extent, indefinitely maintained until necessary.

Sheltered Housing

The house is located in the centre of a village and has capacity for seven users. The main goal is to assist the transition from hospital to community.

It is intended for Coimbra District residents, women and men, aged between 16 and 55, who have difficulties of social reintegration.

The eligibility criteria are: clinical stabilisation and medical care, family support at weekends and ability to integrate into a rehabilitation programme (vocational training, post-placement support, sheltered employment, occupational activities). The activities developed are: personal hygiene, time, medication and money management, cleaning, cooking, shopping, socialisation, leisure activities and use of social support resources and community services. Consumption of alcohol or drugs is expressly forbidden. Users pay 50% of their income (vocational training studentship, wage or social pension) to stay in the residence.

There are two monitors in the residence, one of them from 5pm to midnight and the other one from midnight to 8 am. From 9am to 5pm, users are required to have an occupation. The residence is closed at weekends. If patients are hospitalised, their place in the house is kept until their clinical situation stabilises.

Case analyses and barriers to the restructuring of mental health services

As mentioned by Farkas and Anthony (2010, p. 121) “All too often in the past, preparation became a dead end and individuals languished in sheltered housing, sheltered workshops and day treatment classes forever”. Unfortunately, this is to some extent what we found in our case study.

According to the Report of the National Commission for the Restructuring of Mental Health Services in Portugal (Comissão Nacional para Reestruturação dos Serviços de Saúde Mental em Portugal [CNRSSMP], 2007), “the aim of the new mental health policy is to help individuals to fully recover their life in the community, (...), to ensure access to mental health care for all of those who need it, outside of large institutions and in proximity to the places where people live, and to promote rehabilitation and integration into society (...)"(p. 85). However, the goals of the Report have not been met so far, at least as our case study is concerned. Regarding the vocational training centre, it functions in mental health settings and not in the community, leading some users to make a very long trip to attend the courses. Moreover, we believe that the creation of courses specifically for people with mental illness in mental health settings diminishes the possibility of social contact with people without mental illness, reinforcing the stigma. Besides, the seven courses available do not cover the preferences and capabilities of the whole population of people with mental illness, especially those with higher qualifications, for whom lack of alternatives is the reality. Many trainees of the studied centre had dropped out of university. Instead of the segregated programmes available, we consider that services supporting users to get back to university or other post-secondary education alternatives are more suitable and challenging for a considerable part of the population suffering from mental illness.

Regarding the sheltered work centre, the criticism of the literature stating that sheltered work is segregated and institutional is somehow overcome by allowing workers to provide services for clients in the community. However, it would be beneficial to transform the sheltered work centre into a social firm (Leff & Warner, 2006), integrating people without disability. Moreover, management posts should also be given to patients and career advancement should be possible. In addition, despite the institution aiming to provide training and professional development through sheltered work in order to transfer workers, whenever possible, to competitive employment, evidence suggests that sheltered employment does not contribute, and may block, the goal of competitive employment (Bond, 2004). In our case study, during data collection, no user of the sheltered centre was transferred to the competitive labour market.

Furthermore, The Schizophrenia Patient Outcomes Research Team (PORT) psychosocial treatment recommendations states that any person with schizophrenia who aims to work should be offered supported employment (Dixon et al., 2010). In fact, we can consider the post-placement programme a supported employment service which comprises many principles of IPS: it places people with severe mental illness in competitive employment, provides continued support and assessment, integrates rehabilitation and mental health, attends to consumer job preferences and provides benefits counselling. However, there is a difference worth discussion. Supported employment is conceptualised as a placement-training approach, contrary to the prevocational training practice. Conversely, the institution studied adopts a training-placement paradigm, since the post-placement support programme is closely linked to the vocational training centre, that is, all users that are integrated into it should successfully complete a training course. In other words, contrary to what is expected according to the state of the art, long prevocational training is a *sine qua non* condition to enter the institution's post-placement support programme. According to Bond (1998) there is no evidence supporting prevocational training, since studies failed to show that it helps patients in finding better jobs or maintaining them. In fact, although there might be patients who need preparation before entering the workforce (that should be provided in real world educational settings), there are some for whom spending between 1 to 4 years in training is unnecessary, demotivating and does not really help them in the ultimate goal of finding a job. For instance, training in job searching techniques, implying that users will look for job and contact employers autonomously seems to be ineffective for many people with mental illness (Corrigan, Reedy, Thadani, & Ganet, 1995). Indeed, most people with mental illness need direct assistance in searching for a job (Bond, 1998) and programmes lacking this specific focus have little impact on competitive employment attainment (Bond, 2004).

Besides, it is worth noting that the post-placement programme has capacity for 12 users and vocational training for 58 users, meaning that after the training most users do not have any support to find and maintain employment. So the true basis underpinning this non-mainstream vocational training programme is not clear. Is it a way to help people with mental illness to achieve employment or is it an occupational activity? Therefore, we strongly advocate that resources from courses specifically for people with mental illness in mental health settings are dedicated to the improvement of the quality and capacity of post-placement support programme as well as to the creation of mainstream educational programmes, which are a truly inclusive.

Sheltered housing also presents a number of issues. First of all, users are not eligible if they do not have a place to stay at weekends (e.g., relative's home), since the residence is closed. Second, being a transitional model, it implies a time-limited stay and no other programme to assist people in finding stable housing is available after its deadline. Frequently, when reaching programme completion, many users do not have an individualised housing plan, which sometimes leads them to moving constantly from shelter to shelter. Actually, more than 20 years ago Carling and Ridgway (1987) already ascertained that transitional stay in residential settings creates major difficulties for people with mental illness, including constant moves that lead to a chronic dislocation, and a final return to family, hospital or homelessness, failing, therefore, in supporting individuals to obtain independent and stable homes. In our case study, during data collection no user was transferred to an independent and stable home. The recent Portuguese Decree Law n.º 8/2010 (dated January 28, 2010), modified by the Decree Law n.º 22/2011 (dated February 10, 2011), defined measures for the creation of the National Network for Continuing and Integrated Care in Mental Health, which is characterised by the following multidisciplinary services: residential units of four types varying according to the level of autonomy (residence for training of autonomy; residence with moderate support; residence with maximum support and autonomous residence), domiciliary care and socio-occupational units. Some problems encountered in our case study's residence may be solved by complying with the Decree-Law aforementioned (and the Ordinance n.º 149/2011), which regulates the creation of an individual plan of intervention and residence functioning 24 hours a day, all year long. However, under this legislation the continuum model is still maintained. For instance, the stay in the residence for training of autonomy has a maximum duration of 12 months. Indeed, mobility is a feature of this new legislation, which states that at the expiry of the prescribed stay and the therapeutic goals not being achieved, the manager of the unit must prepare the discharge of the patient and his/her admission to the most appropriate unit or team. Other factors identified in the literature as drawbacks of residential programmes are maintained in this new legislation, namely the combination of housing and treatment, and group living. Moreover, with the exception of the residence for training of autonomy (which is a short-stay unit), admission to the residences requires that the person does not have appropriate family or social support. However, supporting people with mental illness to achieve housing should not be an alternative to family support, but rather a complement. Besides, if we recognise that patients who are severely deteriorated might benefit from these services, a programme to support people with mental illness, whether having family support or not, to achieve their independent living (with flexible supports) in a home of their choice in the normal housing market is still lacking. According to Chilvers, Macdonald and Hayes (2006), although programmes where people with severe mental illness are placed within one site with staff assistance may be helpful for providing a “safe haven”, they may also augment the risk of developing dependence on professionals and exclusion from the society. In fact, after analysing 28 residential units in Portugal, the Team of the Project for Continuing and Integrated Care in Mental Health (Equipa de Projecto de Cuidados Continuados Integrados de Saúde Mental [EPCCISM], n.d.) stated in its activity report of 2010 that users were not appropriately integrated in the community and demonstrated a pronounced dependence on professionals.

Regarding domiciliary care, despite being a beneficial service for people with mental illness who, in fact, have a home, it does not avoid the problem of homelessness or unnecessary institutionalisation of the group who do not have a domicile.

The National Commission for the Restructuring of Mental Health Services in Portugal states in its report (CNRSSMP, 2007) that the needs of autonomy of people with mental illness can best be met by supported housing, since it is an individualised solution, which effectively facilitates participation in social life. However, in our case study this assumption is not being translated into practice and the new legislation on continuing and integrated care for people with mental health problems (Decree Law n.º 8/2010, dated January 28, 2010, modified by the Decree Law n.º 22/2011, dated February 10, 2011) does not provide for its implementation.

More than focusing on skills training and assisting survival in the community, psychiatric rehabilitation promotes a vision of recovery which implies supporting the achievement of a meaningful life in chosen roles and settings (Farkas, 2006, 2007; Farkas & Anthony, 2010). Despite the target institution claiming to base its interventions on recovery values, our analysis raises some questions in this regard. In fact, the institution in question helps people with mental illness by improving their functioning; however it still remains to be determined if they perceive their life to be meaningful. Are people with mental illness in this institution doing what they really want to do? Are they where they want to be? Indeed, most individuals in the institution studied are placed in sheltered settings opposing the person orientation principle of recovery, which implies the promotion of valued roles outside the mental health environment, rather than constraining them to ghettos (Farkas, 2007).

As far as we could ascertain, the studied institution has not yet changed the paradigm of care, a situation that we deem results from barriers found throughout the country in the implementation of the restructuration programme. First of all, the Report of the CNRSSMP (2007) states that scientific research in Portugal in the area of psychiatry and mental health is scarce and presents low competitiveness both at a national and international level. Moreover, most of the institutions providing rehabilitation services do not rigorously assess the quality of their programmes. The Project Team for Continuing and Integrated Care in Mental Health (EPCCISM, n.d.) verified that there was a deficit of quality assessment of the services provided by residential and socio-occupational units in Portugal. In fact, the Activity Report of 2010 (EPCCISM, n.d.) states that, over the last years, there was no regulation regarding the monitoring and evaluation of services, associated with conservative practices and disinvestment in the rehabilitation projects by institutions, leading to a deterioration of their quality.

The Centre for Psychiatric Rehabilitation at Boston University has identified three important elements to implement recovery-oriented psychiatric rehabilitation interventions: culture, commitment and capacity (Farkas & Anthony, 2010; Farkas, Ashcraft, & Anthony, 2008).

As mentioned by Farkas et al. (2008), culture encompasses rules on social and professional interactions. A recovery-oriented intervention presupposes creating a culture of user involvement, which implies a strong partnership between the provider and the user. In our case study, this partnership was not always observed and users were in many circumstances given a passive role in the process of rehabilitation. According to our personal and professional experience, in Portugal the judgment of professionals frequently prevails in the decision-making process and the participation of the persons with mental illness in the planning of their care is minimised. Besides, the judgment of the professionals is characterised by fear and low expectations, a barrier also found in England for the implementation of IPS (Rinaldi, Miller, & Perkins, 2010). According to Farkas and Anthony (2010) some engagement techniques used to demonstrate partnership include accompanying the person in concrete activities (e.g. sports or drinking coffee). In Portugal, that would be frequently seen as unethical or as not respecting the professional boundaries. In general, what our experience has shown is that, in Portugal, there is a power based relationship between mental health providers and patients, in which providers maintain a "one-up" position and patients a "one-down" passive position. Although the new Portuguese mental health programme intends to overcome this situation by involving users in their mental health care, few changes have been in fact verified in daily practice, as experienced by one of the authors, who is both a researcher and a relative of a person with mental illness.

Moreover, a culture based on recovery implies the value of simple human decency, as mentioned by Farkas et al. (2008), which encompasses, for example, how bathrooms in the institutions are organised (for only staff members' or for everyone's use). In our case study, there were different bathrooms for patients and for staff members, the latter locked in order to be inaccessible by users. This represents undoubtedly a form of stigma. It is urgent that professionals understand that fighting the stigma of mental illness and promoting recovery starts with the awareness of their own discriminatory behaviours and the treatment of users as equal human beings.

As explained by Farkas and Anthony (2010), a conviction that resources will exist to make the change is fundamental to commit to a psychiatric rehabilitation project. Despite restructuring of mental health services being a challenge that Portugal is embracing since 2007, the current economic crisis is hindering somewhat its effective implementation. The institution studied is facing serious funding problems being currently at risk of closing the existent programmes. This economic barrier prevents mental health providers from committing themselves to the implementation of new programmes.

The capacity of an organisation to implement a psychiatric rehabilitation intervention is related to staff knowledge and attitudes (Farkas & Anthony, 2010). First of all, we consider that undergraduate and postgraduate curricula of mental health areas are failing to provide training on community mental health services. The University of Coimbra Psychology licentiate and master degrees do not include any kind of theoretical or practical training in psychiatric rehabilitation interventions for people with severe mental illness. Medical students have only one module of psychiatry during their licentiate degree with little or absent coverage of psychiatric rehabilitation. Besides, the predominant focus of specialisation in psychiatry is the psychopharmacological treatment of mental illnesses.

The resistance of staff to change is also a major barrier in Portugal. The receptiveness to change is mentioned by Farkas and Anthony (2010) as a feature of a recovery-based culture. For instance, as exposed by Bond (2004), if a programme embraces the goal of employment in mainstream, most of the staff time should be spent outside the office. A change of this kind would be difficult in Portugal, since most professionals are still trained according to the systems of the past and institutions invest little in their continuing training. Moreover, in many psychosocial services the funding problem hampers hiring qualified professionals (EPCCISM, n.d.).

In short, the failure in complying with the most recent available evidence on psychiatric rehabilitation, the lack of rigorous assessment of rehabilitation programmes outcomes, the low involvement of users in their mental health care planning, conservative practices, the lack of training of professionals in the recovery paradigm, and the severe economic constraints are some of the main barriers to the restructuring of mental health services.

The implementation of a recovery-based practice is vital. Where do people want to live? Where do they want to work? How can we help them in achieving their goals? If these questions are not posed we are failing badly to provide people with mental illness with a meaningful life, which is the ultimate goal of psychiatric rehabilitation. Moreover, implementation of the new mental health plan should not occur without plans for assessment using rigorous methods. To introduce a community mental health care topic in the core curriculum of psychology, medicine and related areas, as well as in the specialisation of psychiatry, along with the continuing education and training of mental health professionals, is of utmost importance to create a future of qualified professionals in community psychiatry. Changes in the funding system of mental health services and more cooperation between researchers, practitioners and mental health policy makers are current challenges for the implementation of the mental health plan proposed in 2007.

Limitations

Although we were given the capacity of each programme as well as the information that for many years they worked at their full capacity, we were informed that the number of people which attend the programmes dropped since 2011, especially in the training centre due to an inability of the institution to pay professionals and the studentships of the trainees. However, we were not officially provided with the exact number of people attending the programmes currently, which we assume is a strong limitation of this work.

Moreover, the manuscript does not provide data on the representativeness of the institution described of the Portuguese experience. However, there is no national study on this subject that can provide an adequate answer. An ongoing study by our team aims to address this knowledge gap.

Future Directions

It is crucial to assess whether programmes are successful in meeting the goals they are designed for and to study user's perspectives and satisfaction with the programmes.

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Capítulo 4

Stigma of severe mental illness:

A barrier to community integration

Abstract

Although a vast number of studies have been carried out and substantial efforts have been made to fight the stigma of severe mental illness, its eradication is still a priority in the agenda of mental health care systems. This review aims at critically analysing the different agents of stigma of mental illness and developing a theoretical framework of the pathways by which these entities hinder the community integration of people with mental illness. The challenges facing mental health care systems resulting from stigma-related barriers are examined. The review shows that people with mental illness worldwide still experience prejudice and discrimination by the public, family, professionals, and employers, which severely impacts their community integration. Families and professionals are both perpetrators and victims of stigma, so that it is urgent to combat the different facets in which stigma is expressed. Indeed, most of the efforts have been made to fight stigma of the public, so that overcoming stigma endorsed, but also suffered, by other groups is a key challenge to mental health professionals, researchers and decision-makers.

Keywords: stigma, community integration, severe mental illness, mental health professionals, anti-stigma interventions.

Introduction

The psychiatric care for people with severe mental illness has changed significantly over the past 50 years. Not long ago, a considerable number of people with mental illness were condemned to spend almost all of their lives in psychiatric hospitals in poor and dehumanised conditions. The process of deinstitutionalisation led to a significant reduction of psychiatric hospitals and to the emergence of community integration efforts. According to Bond, Salyers, Rollins, Rapp, and Zipple (2004), community integration means that people with mental illness abandon the patient role and segregated housing and work settings, and achieve an independent life in mainstream contexts. However, for many people with mental illness, community integration is still an unfulfilled goal and stigmatising attitudes and discriminatory behaviours are among the barriers to the achievement of this outcome. Although there is a vast literature on stigma of mental illness, an analytical review on stigma-related barriers to community integration is still lacking.

This review has three major objectives: 1) To analyse stigma of mental illness endorsed by different sectors of society as a strong barrier to community integration; 2) To summarise in a conceptual framework how different dimensions of stigma can hinder community integration 3) To identify the current challenges facing mental health care systems based on the existing stigma-related barriers.

In order to accomplish these goals, a narrative synthesis of the key literature on stigma of mental illness was carried out.

Electronic databases EMBASE (including EMBASE classic), MEDLINE, PsycINFO were accessed via OVID SP and searched from inception through August 2012. Search strings utilised were: “stigma AND (severe mental illness OR community integration)”. Hand searches of the references of retrieved literature were carried out. We also conducted a college library search through a computerised database using the search terms “stigma” and “community integration”. Internet search through Google was carried out to identify websites of programmes to fight stigma.

The selection of the literature was made through the assessment of pertinence to the purposes of the study and discussion with experts in the field. All studies assessing stigma in populations other than severe mental illness (schizophrenia spectrum disorders), e.g., depression, personality disorders and dementia, and not available in English were excluded. Stigma is analysed cross-culturally and non-western studies were also included.

The theoretical framework was created taking into account the conclusions arrived at in each topic analysed in the synthesis. It aims to be a guidance model for mental health providers, researchers working in the field of stigma, and decision makers.

Stigma and self-stigma: current situation, origins and consequences

Link and Phelan (2001) define stigma as the co-occurrence, in a power situation, of the elements of labeling, stereotyping, separation, status loss, and discrimination. According to Thornicroft, Brohan, Kassam and Lewis-Holmes (2008) stigma comprises three problems: the problem of knowledge (ignorance), the problem of attitudes (prejudice) and the problem of behaviour (discrimination). So, stigma stems from a lack of knowledge associated with stereotyped beliefs, which leads to a negative evaluation (attitudes) and negative feelings (prejudice), which, in turn, result in exclusion and negative actions toward the stigmatised person (discrimination).

Despite the various attempts to combat it in recent years, stigma is still a burden for people with severe mental illness and a strong barrier to their recovery. Brohan, Elgie, Sartorius, and Thornicroft (2010) found in a study across 14 European countries that almost half (41.7%) of the participants (people with schizophrenia or other psychotic disorder) reported moderate or high levels of self-stigma and 69.4% moderate or high perceived discrimination. Thornicroft, Brohan, Rose, Sartorius and Leese (2009) carried out a study with patients in 27 countries and found that negative experienced discrimination was high across countries in areas such as making friends, finding and keeping a job and in intimate relationships. Moreover, this study as well as the study of Uçok and colleagues (2012) revealed that anticipated discrimination prevented people with mental illness from applying for work, training or education and from looking for a close relationship.

Research has shown that prejudice and discrimination endorsed by the public arise from myths that people who suffer from mental illness are dangerous (Corrigan et al., 2002; Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000; Link, Phelan, Bresnahan, Stueve, & Pescosolido, 1999; Pescosolido, Monahan, Link, Stueve, & Kikuzawa, 1999; Thompson et al., 2002; Wolff, Pathare, Craig, & Leff, 1996a;), naive and unable to care for themselves (Corrigan, Edwards, Green, Diwan, & Penn, 2001a), unpredictable (Crisp et al., 2000) and less competent (Pescosolido et al., 1999).

These myths are still installed in our society, although research does not corroborate them. For instance, despite the fact that a statistical relationship exists between schizophrenia and violence, only a small percentage of societal violent behaviour can be ascribed to persons with this condition and 99.97% of those with schizophrenia will not be convicted of serious violence in a given year (Walsh, Buchnan, & Fahy, 2002). Steadman and colleagues (1998) assessed violence in 1136 patients with mental disorders during their first year after discharge from the hospital and in a comparison group of 519 people living in the neighbourhoods in which the patients lived and found no significant difference in the prevalence of violence between the two groups. In both samples, the authors verified that violence occurred most frequently towards family members and friends and that substance abuse significantly raised the prevalence of violence. Appelbaum, Robbins and Monahan (2000) showed that the presence of delusions does not predict higher rates of violence among discharged psychiatric patients. The Team for the Assessment of Psychiatric Services (TAPS) examined the outcomes of a sample of long stay psychiatric patients resettled in the community from 1985 to 1993 and found that just 2% committed serious assaults over the 5 year follow up (Trieman, Leff, & Glover, 1999). Taylor and Gunn (1999) analysed homicides perpetrated by people with mental illness between 1957 and 1995 in UK and found that there was a 3% annual reduction in their contribution to the official statistics, suggesting that care in the community does not represent a risk for society.

The belief that people with mental illness are dangerous is perpetuated by the media and cinema. The major objective of the media is to sell newspapers or increase audience rates (Benbow, 2007) and sensationalism meets this purpose. According to Vahabzadeh, Wittenauer, & Carr (2011), reporting of violent crime and murder committed by people with schizophrenia is overemphasised in U.S. newspapers, whereas few crimes against people with schizophrenia are reported. In the case of cinema, movies such as *Friday the 13th* and *The Silence of the Lambs* reinforce the myth of dangerousness (Leff & Warner 2006; Wedding & Niemiec 2003).

The effects of stigma are devastating and deleterious compromising community integration. Stigmatising attitudes of the public can hinder community integration when residents of a community oppose the creation of accommodation/housing for people with mental illness, the so-called NIMBY (not in my backyard) syndrome (Cowan, 2003; Dear, 1992) or when landlords refuse to rent their properties to people with mental illness (Corrigan, 2000).

Stigma and self-stigma, in other words, when people with mental illness internalise the negative stereotypes and feel they are less valuable than others (Watson & Eack 2011), are related to poor self-experience (Lysaker, Buck, Taylor, & Roe, 2008a), poor self-esteem (Lysaker, Tsai, Yanos, & Roe, 2008b), higher levels of positive symptoms (Lysaker, Davis, Warman, Strasburger, & Beattie, 2007) and impact vocational outcomes (Yanos, Lysaker, & Roe, 2010).

Lysaker and colleagues (2008a) showed that people who have greater levels of social distance or withdrawal as a result of stigma tend to view themselves as less lovable. Staring, Van der Gaag, Van den Berge, Duivenvoorden, and Mulder (2009) found that stigma moderates the associations of insight with depressed mood, low self-esteem and low quality of life in people with schizophrenia. The authors demonstrated that patients presenting better insight along with stigmatising beliefs are more likely to experience low quality of life, negative self-esteem and depressed mood.

Livingston and Boyd (2010) conducted a meta-analysis on correlates and consequences of internalised stigma that showed a strong negative relationship between internalised stigma and hope, self-esteem and empowerment. The authors also demonstrated that internalised stigma was positively associated with psychiatric symptom severity and negatively associated with treatment adherence.

Indeed, stigma contributes to the low rates of help-seeking among people with mental illness (Benbow, 2007), either because they try to avoid discrimination by not using psychiatric services (Corrigan, 2004; Hayward & Bright, 1997) or due to internalised stigma (Fung, Tsang, & Corrigan, 2008). Cape and McCulloch (1999) studied patients' self-reported motives for not revealing psychological problems in consultations with General Practitioners (GP). From the 83 patients assessed, 64 admitted that they had not disclosed their emotional problems and 45% of these stated shame or hesitation to bother the GP as the main reasons. Tsang, Fung, and Chung (2010) reported that individuals with higher global functioning, better readiness for action and lower level of self-stigma demonstrated better treatment participation. The findings of Fung, Tsang, and Chan (2010) using path analysis corroborated direct and indirect (mediated by insight and readiness for change) effects of self-stigma on reducing treatment adherence.

In short, stigma endorsed by the public towards people with mental illness can constitute a barrier to community integration when residents combat the creation of housing facilities or landlords refuse renting their properties to people with mental illness. On the other hand, the internalisation of stigmatising attitudes by the persons with mental illness themselves constitutes an obstacle to their empowerment and consequently leads to poor self-esteem and a lack of motivation, confidence and hope to engage with treatment and to pursue meaningful goals, which definitely opposes community integration (the conclusion is illustrated in Figure 1).

Stigma endorsed by family and professionals

As we will discuss later, social contact with people with mental illness helps to reduce stigma, so one might expect that professionals and families would not endorse stigma. Nonetheless, research has shown high levels of negative expressed emotion (EE) in attitudes of relatives (measured by critical comments, hostility and overinvolvement) and their association with relapse rates (Brown, Birley, & Wing, 1972; Vaughn & Leff, 1976). This finding is understandable if we consider that families, like the general public, also have the problem of ignorance. Butzlaff and Hooley (1998) conducted a meta-analysis of all available EE studies in schizophrenia in order to address the question of its predictive validity and confirmed that EE is a significant and robust predictor of relapse in schizophrenia (Figure 1).

More unexpected, one of the main challenges nowadays is to overcome stigma endorsed by professionals (who, in principle, do not have the problem of ignorance) and the prejudice and discrimination that may arise as a consequence of their practice, in other words, iatrogenic stigma (Sartorius, 2002a). Patients frequently state that their interactions with general and mental healthcare personnel demonstrate levels of ignorance, prejudice and discrimination (Thornicroft et al., 2008). Besides, high levels of EE can also be found among professionals (Willets & Leff 1997). The review conducted by Schulze (2007) showed that about three quarters of the publications show that attitudes of mental health professionals do not diverge from those of the general public, or are even more negative.

Nordt, Rossler, & Lauber (2006) conducted a study in Switzerland comparing attitudes towards people with mental illness between the general public and mental health professionals and concluded that the two groups did not differ in terms of negative stereotypes. Surprisingly, the group of psychiatrists had more negative stereotypes than the general population. The same study showed that the social distance towards someone with schizophrenia was as high in all professional groups as in the public. This finding was previously demonstrated by Lauber, Anthony, Ajdacic-Gross, and Rössler (2004). Űçok, Polat, Sartorius, Erkoc, and Atakli, (2004) investigated attitudes of psychiatrists toward patients with schizophrenia and found that they believed that the likelihood of rehabilitation for schizophrenia was 56%. In the same study, 43% of psychiatrists reported that they would not visit a patient at his/her home, and 55.2% expressed discomfort when they found a patient with schizophrenia at a social event.

The study of Magliano and colleagues (2004) carried out in 30 Italian mental health services found that 63% of the nurses and 43% of the psychiatrists thought that patients with schizophrenia should not get married. A study in Beijing revealed that 63% of psychiatric hospitals nurses agreed that people with mental illness need the same form of control as a young child (Sévigny et al., 1999). In Japan, Hori, Richards, Kawamoto, and Kunugi (2011) assessed attitudes towards schizophrenia among psychiatrists, psychiatric staff (other than psychiatrists), the general population and physicians (other than psychiatrists). The study showed that psychiatrists had the least negative attitudes towards schizophrenia, which was followed by the psychiatric staff, and attitudes of the general population and of physicians were equally stigmatizing. However, the four participant groups had the same degree of scepticism regarding treatment of patients with schizophrenia.

Rinaldi, Miller, and Perkins (2010) reviewed the evidence for the implementation of the individual placement and support (IPS) approach in England and showed that, despite being an evidence-based practice (Bond, 2004) to help people with mental illness to gain and retain competitive employment, it is poorly developed in England. According to the authors, fear on the part of professionals, individuals and their families and a culture of low expectations are among the barriers to implement IPS in England. In fact, mental health professionals may underestimate the skills, experience and capabilities of their patients and overestimate the risk to employers (Rinaldi et al., 2008).

Another factor that might hinder community integration is the fact that many professionals are still trained in the systems of the past, characterised by a more paternalistic approach in protected settings. The challenge is to change the attitudes of staff to fit the new philosophy of care (King, 1993; Leff & Warner, 2006), which entails that professionals recognize that users (and their carers) have equal status as them and possess power over their own lives.

Researchers on mental illness are not immune to stigma as well. For instance, in the research on stigma, public opinion surveys have been much more frequent than studies directly assessing the experience of stigma of people with mental illness (Switaj, Wciórka, Smolarska-Switaj, & Grygiel, 2009). According to Sartorius (2002b), this has to do, to some extent, with the attitudes of the researchers who also see people with mental illness as unreliable sources of information.

In brief, the negative attitudes held by professionals will affect the quality of the services they provide, disempower patients and severely impact recovery outcomes (Watson & Eack, 2011). Moreover, community integration will not be possible if professionals do not believe in users’ potential and do not give them the conditions to develop it (these findings are summarised in Fig. 1).

Mental illness, work and stigma

Studies have demonstrated the clinical and other non-vocational benefits, such as quality of life and self-esteem, of work for people with mental illness (Dunn, Wewiorski, & Rogers, 2008, Eklund, Hansson, & Bejerholm, 2001; Mueser et al., 1997). Also, the cost-effectiveness of the work of people with mental illness is demonstrated. Bush, Drake, Xie, McHugo, and Haslett (2009) calculated annual costs of ambulatory and institutional services for 187 patients with long-term psychotic illness and co-occurring substance misuse and analysed group differences in ten-year utilisation and cost. Two groups were compared: a steady-work group (N=51) which integrated people who worked an average of 5,060 hours over ten years and a minimum-work group (N=136). The authors ascertained that a significant decrease in service use was associated with steady employment. Moreover, the cost reduced significantly more for the steady-work than for the minimum-work group.

Leff and Warner (2006) reported that 50%-60% of people with serious mental illness are capable of employment, but in the USA and Britain just around 15% of this group is in any kind of paid work.

Perkins and Rinaldi (2002) examined the vocational status of people with prolonged mental illness in the inner London Borough of Wandsworth over 10 years and demonstrated that unemployment among people with long-term mental health problems increased from 80% in 1990 to 92% in 1999, and that the unemployment rates among those with a diagnosis of schizophrenia increased from 88% in 1990 to 96% in 1999.

According to Marwaha and Johnson (2004) the employment rate in schizophrenia appears to have declined over the last 50 years in the UK and demonstrated that stigma, discrimination, fear of loss of benefits and lack of appropriate professional help are the main barriers to obtaining employment among this population. It is noteworthy that unemployment is not just an issue regarding chronic patients, but also compromises first-episode psychosis patients. The review of Marwaha and Johnson (2004) showed that in most studies the majority of people presenting to services for the first time are already unemployed. Only 35.0% of first-episode psychosis patients in the study by Ramsay, Stewart, and Compton (2012) reported having paid employment during the month prior to hospitalization, which is considerably lower than the rate of employment during the same period in the two counties in which the study was carried out. A study in Dublin, Ireland, found that just 46% of individuals with first-episode psychosis were employed (Turner et al., 2009).

The low rates of short-listing, hiring, salary, the poor promotion prospects and the high rates of dismissal (G. Thornicroft, personal communication in a lecture on 21st March 2012) leads to a dilemma: conceal or disclose. Wheat, Brohan, Henderson, & Thornicroft (2010) stated that many doctors, being aware of discrimination on the part of employers, advise their patients to conceal their mental illness, although this situation may have negative consequences, for instance the possibility of dismissal if the medical condition is not disclosed.

The challenge to mental health care systems is to make available the evidence-based programmes to help people with severe mental illness to get and maintain a job.

However, the success of these programmes depends on several factors which touch different dimensions of stigma: the collaboration of employers, who will decide to hire people with mental problems and adjust the work setting to fit them, of professionals, who should take into account the potential of their patients, the system of benefits, in order that people do not feel penalised for returning to work, and on the availability of funding to establish the programmes.

Associative stigma

Professionals and families are not just perpetrators of stigma, but also victims of it. Unlike stigma experienced by people who suffer from mental illness, almost no attention has been paid to mental health professionals and families, who suffer from stigma by association, the so-called courtesy stigma (Goffman, 1963). Associative stigma "describes the process of being stigmatised based on a close association with a person with mental illness, typically a family member - as if the family was somehow tainted by the relationship. Similarly, a mental health care worker may also be stigmatised based on a work relationship" (Halter, 2008, p. 20).

In line with this concept is the position of Sartorius (1998, 2006a) on the centrifugal tendencies of mental illness stigmatisation. According to the author, stigma also affects the family of the person who has a mental illness, psychiatrists, researchers, mental health services and the methods of treatment, leading to a lack of investment in the care of this population and to inadequate research funding.

Associative stigma affects families who withdraw from their own social networks, leading to the dual effect of losing support and restricting the user's social relationships (Leff & Warner, 2006). It is noteworthy that not only does stigma impair social networks, but the other way round is also true. Sibitz and colleagues (2011) showed that a poorer social network leads to higher internalised and perceived stigma and lower empowerment, which results in depression and, in turn, low quality of life.

Associative stigma also affects professionals and was found to be related to depersonalisation, emotional exhaustion, and less job satisfaction (Verhaeghe & Bracke, 2012).

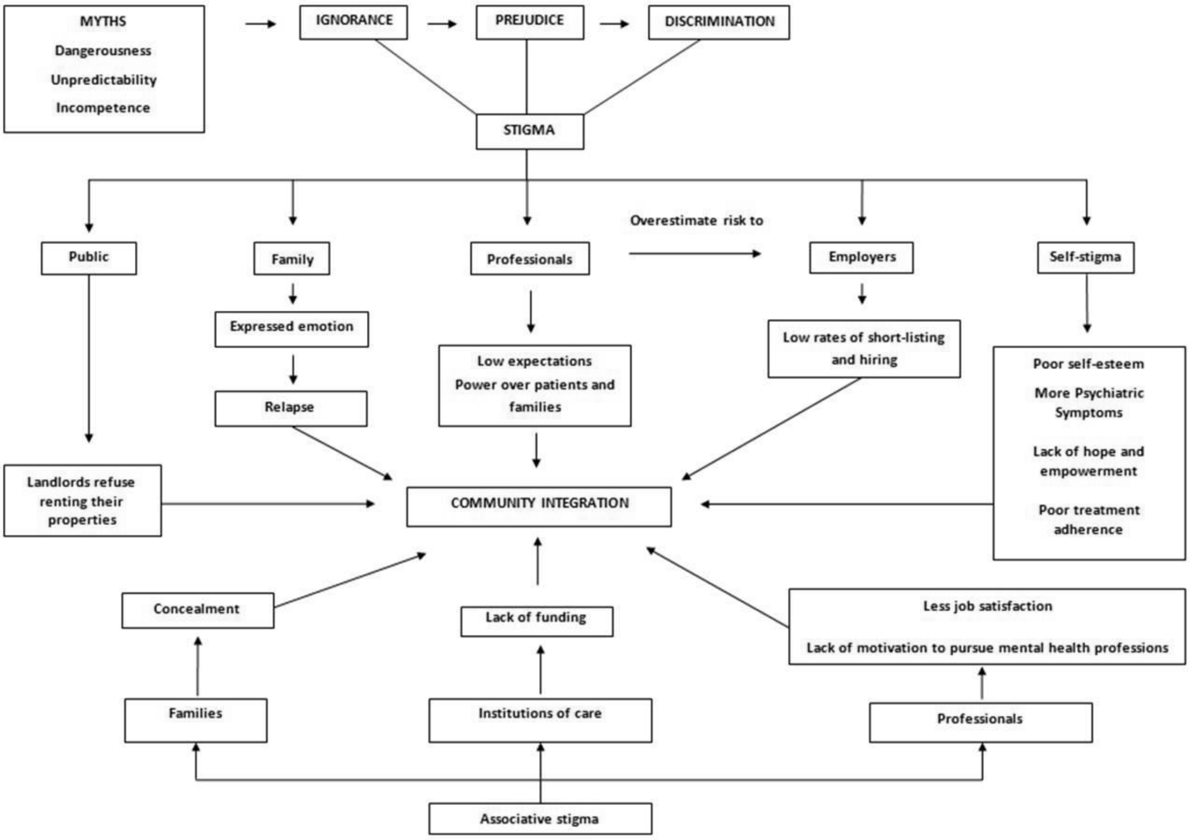
Public opinions about psychiatric settings and psychiatrists have been time after time negative during the past decades (Sartorius et al., 2010). Roberts (2010) analysed a collection of papers and verified that stigma is linked to psychiatry and psychiatric education across several countries. The author showed that physicians in training in Colombia, Romania, Saudi Arabia and Spain hold harsh attitudes toward trainees in or approaching psychiatry. For instance, many participants stated that medical students risk being perceived as odd, peculiar or neurotic if they show interest in psychiatry. Family, colleagues and even the medical school express disapproval to those who wish to pursue a psychiatric career.

Halter (2008) examined the attitudes of nurses toward colleagues who have chosen a career in psychiatric/mental health nursing. Participants were asked to rate nursing specialty areas from their own personal preference and from their beliefs of society's perspective. Psychiatric nursing was classified as the area least preferred either in participants' personal preference or in their perceived perspective of society. In the same study, psychiatric nurses were more often described as idle, disrespected and unskilled.

A complete review on the image of psychiatry and psychiatrists conveyed by the media and also on opinions about psychiatry and psychiatrists of the general public, of students of medicine, of health professionals other than psychiatrists and of persons with mental illness and their families can be found in Sartorius and colleagues' work (2010).

In summary, associative stigma will block community integration in different ways. First of all, it is important to mention that social support networks are key elements for community integration, so that the concealment and withdrawal of families as a result of associative stigma will trigger the loss of social support. Secondly, professionals are essential stakeholders in the struggle for a vision of care that promotes community integration and some enthusiastic professionals may avoid psychiatry as a career to shun the stigma of the public, colleagues and even of their families. Moreover, stigma can lead to less job satisfaction, which may impact the services provided. Finally, associative stigma causes a lack of funding of the institutions of care and research projects in the area of mental illness, hindering innovation in mental health care. Thus, all of the situations aforementioned constitute, in different ways, obstacles to a paradigm of care based on community integration (these conclusions are illustrated in Figure 1).

Figure 1 – Conceptual framework: pathways in which the different agents of stigma hinder community integration.



Programmes to reduce stigma

Fighting stigma is one of the biggest challenges of community mental health systems aiming to promote community integration of people with severe mental illness, since it involves overcoming centuries of prejudice and discrimination (Benbow, 2007).

Some initiatives have been taken to reduce stigma worldwide. In England, a five-year campaign entitled “Changing Minds: Every Family in the Land” was launched in

1998 by the Royal College of Psychiatrists (Crisp, Cowan, & Hart, 2004). In 2009, the largest ever programme in England to fight stigma against people with mental health problems was launched. The programme is called “Time to Change” and is being run by three charities: Mental Health Media, MIND and Rethink (Henderson & Thornicroft 2009; http://www.time-to-change.org.uk/). In the United States, the National Alliance on Mental Illness developed in 1996 a contact based anti-stigma programme called “In Our Own Voice”, firstly called “Living with Schizophrenia” (http://www.nami.org/template.cfm?section=In_Our_Own_Voice). In 1996, the World Psychiatric Association (WPA) launched an international programme to fight stigma and discrimination because of schizophrenia called “Open the Doors”, which is implemented in about 20 countries worldwide (Sartorius, 2006b; http://www.openthedoors.com/). “Open the Doors” is a long term programme and involves different social sectors, for instance, health ministries, social welfare services, labour ministries, non-governmental organisations, and the media (Sartorius, 2002a). The results of these programmes and campaigns are not homogeneous and their effectiveness on the population level is not well known. Despite the UK Royal College of Psychiatrists reporting positive evidence (Crisp et al., 2004) and the decreasing of experiences of discrimination reported by users after the “Time to Change” programme was launched (Henderson et al., 2012), the evaluation of the German WPA Programme “Open the Doors” provided limited evidence for the efficacy of anti-stigma campaigns on the population level (Gaebel et al., 2008). Moreover, in spite of the various approaches aimed at reducing stigma throughout the United States, Silton, Flannelly, Milstein, and Vaaler (2011) found that the desire for social distance toward persons with schizophrenia was higher in 2006 than 1996.

Small-scale interventions appear to produce positive outcomes. Indeed, taking into account the experience of implementation of “Open the Doors”, Sartorius (2006b) argues that the goals of such programmes should be broadly formulated, but specific plans for immediate application have to be modest in size and locally relevant. An example of this principle is the small educational campaign focused on the neighbours of a new residence for discharged long-stay patients conducted by Wolff, Pathare, Craig and Leff (1996b). Besides the didactic part (an information pack containing a video and information sheets), the campaign also included a social component (e.g., social events). Compared with a control group, the neighbourhood where the campaign took place showed an overall decrease in measures of fear and exclusion. Moreover, neighbours in the experimental area were more likely to make contact with patients.

Another example of a small-scale intervention with a target group consisted in a community education programme delivered by users, carers and mental health staff to police officers (Pinfold et al., 2003). Despite the belief of dangerousness not suffering a significant change, the programme was successful in raising awareness on mental illness, such us regarding the possibility of recovery, and in improving communication skills to work with people with mental illness.

Other attempts to reduce stigma have been carried out. Ando, Clement, Barley, and Thornicroft (2011) did a systematic review of the studies on methods to simulate the auditory and visual hallucinations experienced by people with schizophrenia in order to enhance empathy and comprehension towards those with this disorder. The authors explored the effectiveness of simulated hallucinations in stigma reduction and concluded that even though simulated hallucinations enhance empathy towards people with schizophrenia, they also increase the reluctance for social contact.

Corrigan and Penn (1999) grouped strategies to combat stigma into three processes: protest, education and contact. Results of a randomised controlled study conducted by Corrigan and colleagues (2001b) found that protest yielded no significant change in stigmatising attitudes. Despite the finding that participation in the education condition produced a significant change in stigmatising attitudes, the contact condition was superior (this result was confirmed by Corrigan et al., 2002 and by Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012). In Wolff and colleagues' study (1996b) it was social contact which was directly associated with improved attitudes rather than education by itself. Corrigan and colleagues (2010) demonstrated that the two "In Our Own Voice" (a contact programme) conditions produced significantly better results than education.

However, social contact theory has been controversial. The study of Crisp and colleagues (2000) demonstrated that those who reported knowing someone with mental illness were as likely as others to endorse negative statements about the dangerousness of people with schizophrenia. In a study with a sample of mainly African Americans, participants with higher levels of contact showed lower levels of negative affect and less social distance toward individuals with mental illness, but ascribed them higher levels of dangerousness (Graves, Chandon, & Cassisi, 2011). Apart from the context of work, the intervention conducted by Pinfold and colleagues (2003) which put police officers in contact with people with mental illness was not effective in augmenting the reported social interaction ability. The Framework Integrating Normative Influences on Stigma (FINIS), developed by Pescosolido, Martin, Lang, and Olafsdottir (2008), stresses the quality and nature of the contact so that only programmes where social network interactions are continuous, meaningful and positive are likely to have a prolonged influence. It is noteworthy that the meta-analysis carried out by Corrigan and colleagues

(2012) shows that education is more effective than contact at decreasing stigma of adolescents. Moreover, as previously exposed in this paper, the literature shows that stigmatising attitudes and discriminatory behaviours towards people with mental illness are also found among mental health professionals, a fact which opposes social contact theory. Hence, the question of contact and its repercussion on stigmatising attitudes is not completely resolved.

Some initiatives were mounted to reduce stigma held by professionals. For instance, Willets and Leff (2003) carried out and evaluated a training programme for staff of a residential unit for ‘difficult to place’ mentally ill patients, which emphasized a noncritical approach. The authors verified that the programme was effective in increasing knowledge and skills of staff and could be used with a variety of psychiatric professionals. These experiences should be repeated, but the resistance of staff to participate is a major barrier. For example, the attendance of senior staff members in Willets and Leff study was poor.

Finally, it is important to stress the position of Sartorius (1998), who recommends that psychiatrists should examine their own attitudes and try to increase their tolerance and capacity to deal with schizophrenia. Interventions carried out in small groups or on a one to one basis aiming at making medical staff, including psychiatrists, aware of their stigmatising behaviour seem to be effective (Sartorius, 2002b).

In relation to family, we are failing to provide families the interventions that we know are effective. Several studies showed that psychoeducational family work (Kuipers, Leff, & Lam, 2002; Leff, 2005) leads to a reduction of critical and overinvolved attitudes of family carers, to an increase of treatment compliance and to a diminution of relapse rates (Berkowitz, Shavit, & Leff, 1990; Dixon, Adams, & Lucksted, 2000; Leff et al., 1990; Ran et al., 2003, Rummel-Kludge & Kissling, 2008). Magliano and colleagues (2005) implemented and assessed a psychoeducational family intervention in six European countries. At the one year follow-up, the authors verified a significant enhancement of patients' clinical status and social functioning and a significant decline of relatives' burden. However, professionals reported difficulties in the implementation of the intervention such as overwork, the difficulty to combine family work with other tasks, and the poor allowance of time from the service to run the intervention.

Regarding the great difficulty of work integration, Thornicroft and colleagues (2008) have pointed out that mental health services must work with employers in order that proper adjustments in the workplace are made for people with mental illness. "Time to Challenge" is a project within the programme "Time to Change" to increase employers' knowledge of discrimination against people with mental illness with respect to employment (Henderson & Thornicroft 2009).

There is very little research on strategies to reduce self-stigma and its consequences. Wieczynski (2000) created and evaluated a three session stigma management group based on psychoeducation for 27 inpatients. The results showed that there was no significant enhancement in patients' self-efficacy and stigma coping skills. Link, Struening, Neese-Todd, Asmussen, and Phelan (2002) implemented a 16-session psychoeducation-based intervention with 88 members of a psychiatric rehabilitation clubhouse programme with different psychiatric diagnoses. The educational format and the use of a range of diagnoses may have limited the study. Knight, Wykes, and

Hayward (2006) evaluated a group intervention based on cognitive behavioural therapy to challenge the fairness and acceptance of the stigma perceptions in 21 individuals with schizophrenia. The size of the effect on self-esteem (the primary outcome measure), despite being significant, was small, and reduced to a non-significant trend after a short follow-up period. Macinnes and Lewis (2008) examined the impact of a six-session programme on self-stigma of people with serious mental health problems. Although there was a significant reduction in self-stigma, the results of the study are limited due to the small sample size and the lack of a comparison group.

Fung, Tsang, and Cheung (2011) developed a self-stigma reduction programme that included psychoeducation, cognitive behavioural therapy, motivational interviewing, social skills training and goal attainment programme and tested it in a randomised trial. The results showed that the programme led to a modest improvement of self-esteem, a promotion of readiness for change and an increasing of psychosocial treatment adherence among the self-stigmatised individuals with schizophrenia during the interventional stage. Nevertheless, the effects were not observed during the 6-month follow-up period.

Recently, a manualised group-based intervention integrating psychoeducation, cognitive restructuring and narrative based practices, which is designated Narrative Enhancement/Cognitive Therapy (NECT), was developed and tested in a small randomised controlled trial by Yanos, Roe, West, Smith, and Lysaker (2012). The trial demonstrated its feasibility and tolerability and although no significant differences or trends were evident when comparing NECT with a treatment as usual group (probably due to small sample sizes), when comparing participants exposed to NECT with participants unexposed, the first group showed a trend to have a superior improvement of self-stigma (more stigma resistance and less agreement with stigmatising views).

Finally, it is noteworthy that Brohan and colleagues (2010) found that empowerment and a higher number of social contacts were both significantly associated with a decrease in self-stigma, so effective interventions should target these components.

Regarding associative stigma, the WPA (Sartorius et al., 2010) recommends actions that national psychiatric societies should take to combat the stigmatisation of psychiatry and psychiatrists. These actions encompass defining best practices of psychiatry and ensure rapid action in instances of human rights violations in its practice; revising the curricula for undergraduate and postgraduate medical training, in order to implement teaching methods that could make the subject of psychiatry more attractive (e.g., contact with people who recovered from mental illness); collaborating with patient and family organisations and establishing and maintaining working relationships with the media. Sartorius and colleagues (2010) also stress that the behaviour of psychiatrists in their clinical practice is vital for their image: they should establish a respectful relationship with patients and their relatives, to strictly comply with ethical rules in the practice of psychiatry and to keep up to date with the advances of psychiatric research and practice.

Table 1 – Stigma-related barriers and challenges facing mental health care systems.

Stigma-related barriers to community care	Challenges to mental health care systems
Stigma of the public	To change the image of people with mental illness conveyed by the media To study the factors underpinning the success of social contact in reducing stigma
Stigma of professionals	To make professionals aware of their stigmatising attitudes To train professionals according to the new philosophy of care To study the factors behind the refutation of social contact theory among mental health professionals
Stigma of families	To implement family work, which implies giving professionals proper training and allowing them time to run the intervention
Stigma of employers	To improve collaboration between mental health services and employers To enhance awareness of mental illness in the workplace
Self-stigma	To develop evidence-based psychological interventions to address self-stigma and to promote social contacts To empower people with mental illness and their caregivers
Associative stigma: families	To promote the union of families, trying to avoid their withdrawal from society
Associative stigma: professionals and institutions	Professionals and institutions of care should strictly comply with high standards of care and ethical rules To revise the curricula of undergraduate and postgraduate medical and other mental health professions training To work with the media in order to change the current conveyed image of psychiatry

Conclusion

We carried out a narrative review and the selection of papers was based on the author and some experts' evaluation of relevance, which we assume being a strong limitation of this work. Moreover, the fact that most research on stigma are public surveys, rather than studies directly assessing the experience of stigma of people with mental illness and their carers, limits the synthesis.

However, we explored substantial issues which can inform mental health professionals, researchers, decision-makers, and user and family organisations. Care for people with mental illness is more than ameliorating symptoms; it also involves treating users as fully entitled to citizenship rights. As mentioned by Bond and colleagues (Bond et. al., 2004) "Community integration involves being *of* the community and not just physically located *in* the community" (p. 572). However, stigmatising attitudes endorsed by different groups of society, including the persons who suffer from mental illness themselves, make community integration an unrealised goal worldwide. This reality imposes challenges to community mental health care systems, namely to reduce stigma in its different facets: the stigma of the public to make it possible for people with mental illness not just living *in*, but also being part *of* the community; the stigma of professionals in order that services of quality are provided and the potential of users is taken into account; and the stigma of employers in order to increase employment rates among people with mental illness. The development of interventions to tackle self-stigma is of decisive importance to promote help-seeking behaviour and the necessary self-confidence to pursue meaningful goals in life. Besides, reducing expressed emotion of the family is essential to prevent relapse rates. However, more professionals need to be trained in this intervention and modifications in the services should be done to include it in its routine.

Tackling stigma towards professionals and institutions of care is fundamental to increase funding and to not prevent motivated people from choosing psychiatry as a career. It is also vital to address associative stigma towards families, so that their withdrawal is prevented.

Finally, it is important to emphasize that the development of programmes to tackle stigma exhibited by the different groups addressed in this review are much fewer than those aimed at combating stigma of the public. Therefore there is a strong case for the development of more interventions and their implementation to fight stigma endorsed by professionals, families, employers, the patients themselves, and to combat associative stigma. Social contact theory does not apply to mental health professionals and families, so that more research on what specific characteristics of social contact underpin stigma outcomes is of utmost importance.

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Discussão Geral

Os diferentes estudos que constituem esta tese mostram-nos resultados importantes sobre o estado atual da reabilitação psicossocial em Portugal e das barreiras existentes ao seu desenvolvimento. Os resultados remetem-nos para uma reflexão sobre o papel dos profissionais, inclusivamente dos profissionais de aconselhamento, no processo de reabilitação e sobre os desafios que se lhes colocam com a implementação do novo paradigma de cuidados.

Como mencionam Farkas e Anthony (2010, p.121) "Muito frequente no passado, a preparação (para a inserção na comunidade) tornava-se um beco sem saída e os indivíduos definhavam em habitações protegidas, oficinas protegidas e em unidades de tratamento de dia (de natureza ocupacional) para sempre". Infelizmente, os trabalhos desenvolvidos no âmbito da presente tese permitiram-nos verificar que, no nosso país, esta é, ainda, até certo ponto, a realidade presente. Como vimos no capítulo 1, a grande maioria dos programas de reabilitação nas áreas da educação e emprego é constituída por cursos de formação profissional específicos para pessoas com incapacidades. No entanto, o estudo descrito no capítulo 2 mostra que apesar dos indivíduos em programas de formação profissional apresentarem níveis mais elevados de funcionamento social e ocupacional do que aqueles que frequentavam atividades ocupacionais, diferenças significativas não foram encontradas entre os indivíduos em formação e os indivíduos sem qualquer atividade (não esquecendo que estes se encontravam desempregados). Além disso, o estudo não demonstrou diferenças significativas na qualidade de vida entre os três grupos. Apesar de este ser um estudo meramente exploratório, com todas as limitações que lhe são inerentes, não podemos deixar de refletir sobre estes achados. Ainda que não possamos estabelecer relações de causalidade, o fato é que, em termos sociais e ocupacionais, os indivíduos em formação não funcionavam melhor do que um grupo de indivíduos que estavam desempregados e que não frequentavam qualquer programa de reabilitação psicossocial.

Vimos também no capítulo 1 que 92.9% das instituições portugueses avaliadas prestam atividades ocupacionais, mas o estudo descrito no capítulo 2 falhou em mostrar diferenças em termos de qualidade de vida e de funcionamento global, social e ocupacional entre pessoas com doença mental que participavam em atividades ocupacionais e pessoas com doença mental que não frequentavam qualquer programa de reabilitação. Uma variável que pode também ter contribuído para este resultado desencorajador é o facto de 71.4% das pessoas em atividades ocupacionais viverem em residências de grupo supervisionadas, enquanto apenas 20% das pessoas pertencentes ao grupo que não frequentava qualquer programa de reabilitação viviam nesse tipo de respostas habitacionais. Mas, mais uma vez, e reiterando a fragilidade de um estudo transversal, estes resultados falham em mostrar possíveis efeitos benéficos advindos da participação em atividades ocupacionais. Além disso, tendo em conta a percentagem elevada de pessoas em atividades ocupacionais que viviam em residências supervisionadas e os resultados desencorajadores deste grupo, podemos inferir, com precaução, que estas respostas habitacionais também falham em afetar positivamente os resultados avaliados. No entanto, estudos longitudinais controlados são necessários para confirmar estas hipóteses. Mas, a questão fundamental que aqui se coloca é se podemos continuar a investir em programas sem efetividade demonstrada. Por um lado, o país não investe em estudos de efetividade e, por outro, não implementa os programas com efetividade demonstrada internacionalmente.

De acordo com o Relatório da Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental (2007), a investigação em Portugal na área da saúde mental é escassa. Além disso, apenas uma pequena percentagem das organizações que prestam serviços de reabilitação está envolvida em projetos de investigação (Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental, 2007), e nem todas avaliam a qualidade dos programas desenvolvidos e os resultados obtidos (Equipa de Projecto de Cuidados Continuados Integrados de Saúde Mental, n.d.). A inexistência de uma cultura de avaliação de serviços é, sem dúvida, um fator impeditivo do seu desenvolvimento. E note-se que não é suficiente avaliar os serviços em termos da descrição quantitativa do que é feito, como conhecer, por exemplo, o número de cursos de formação e de pessoas que os frequentam. É fundamental avaliar se eles cumprem as funções a que se destinam. Se uma entidade presta cursos de formação profissional com o objetivo último de integrar a pessoa com doença mental no mercado normal de trabalho, a avaliação da sua eficácia passa por saber quantas pessoas foram, de facto, integradas profissionalmente. A avaliação dos serviços envolve também avaliar a satisfação relativamente aos mesmos e no caso dos serviços de reabilitação implica perceber se as pessoas estão satisfeitas nos papéis que desempenham.

A existência de recursos é essencial para a implementação e avaliação de projetos de reabilitação psiquiátrica e, de facto, a atual conjuntura económica do país não é favorável a tal desiderato. No entanto, defendemos que o investimento financeiro feito em programas educacionais e habitacionais segregadores sejam redirecionados para intervenções que facilitem a integração comunitária.

Em relação ao emprego, o estudo nacional descrito no capítulo 1 mostrou que, de facto, existem algumas experiências de emprego apoiado nas instituições avaliadas, mas nenhuma instituição demonstrou ter o modelo de apoio e colocação individuais de emprego apoiado (*individual placement and support model of supported employement*). Tendo em conta que as recomendações internacionais preconizam que todas as pessoas com esquizofrenia, que tenham o objetivo de trabalhar, devem receber serviços de emprego apoiado, de preferência colocação e apoio individuais, estes resultados também não são animadores. No entanto, existem algumas empresas sociais no país, que, apesar de insuficientes face às necessidades, não deixam de representar um ponto positivo no campo da reabilitação psicossocial.

Deste modo, verificamos que os serviços de reabilitação portugueses são maioritariamente caracterizados por contextos educacionais segregadores e respostas habitacionais caracterizadas por unidades, da propriedade dos serviços, para a vida em grupo de pessoas com doença mental. Estes modelos são obsoletos e a literatura mostra claramente que não favorecem a integração comunitária e a recuperação (*recovery*) das pessoas com problemas de saúde mental. A investigação científica mostra que, com o devido apoio, as pessoas com doença mental têm a capacidade para frequentar as instituições de ensino regulares (Rogers, Kash-MacDonald, Bruker, & Maru, 2010), de viver em habitações da sua escolha no mercado normal de habitação (Rogers, Kash-MacDonald, Olschewski, 2009), e de trabalhar em mercado competitivo (Bond, 2004).

Assim, passados seis anos desde a publicação do Plano de Ação para o Desenvolvimento e Reestruturação dos Serviços de Saúde Mental (Comissão Nacional para a Reestruturação dos Serviços de Saúde Mental, 2007) ainda muito continua por fazer.

Após o lançamento do respetivo plano criou-se nova legislação, nomeadamente a respeito dos cuidados continuados e integrados em saúde mental e de apoio ao emprego e qualificação das pessoas com deficiências e incapacidades. No entanto, continuam ausentes da legislação, e desconhecidos por uma boa parte dos profissionais portugueses que trabalham na área da reabilitação, programas importantes baseados na evidência como sejam o programa de habitação apoiada (*supported housing*), o de colocação e apoio individuais (*individual placement and support*), bem como práticas consideradas promissoras, nomeadamente a de educação apoiada (*suported education*).

No estudo descrito no capítulo 1, verificamos haver por parte de alguns profissionais desconhecimento face aos referidos programas, chegando-nos mesmo comentários referindo que o inquérito era uma boa tentativa, mas que os termos utilizados não correspondiam a programas existentes, nem previstos na legislação. A questão é que os programas existem e são comprovadamente eficazes, mas por falta de conhecimento adequado, não se encontram legislados. Esta falta de atualização permanente quer de profissionais, quer de legisladores, é, sem dúvida, uma grande barreira ao progresso dos cuidados de saúde mental. Tal como vimos no capítulo introdutório, no que diz respeito aos legisladores, e particularmente no caso da legislação de apoio ao emprego e qualificação das pessoas com deficiências e incapacidades, as fragilidades são notórias.

Algumas dessas fragilidades reportam-se nomeadamente aos seguintes aspectos: a) não estarem previstos programas específicos para os diferentes sub-grupos enquadrados no grupo de pessoas com incapacidades; b) o apoio prestado para ajudar as pessoas com incapacidades a manter o emprego obtido ser de tempo limitado; c) formulação de uma definição confusa e generalista de emprego apoiado, que coloca estágios de inserção, contratos de emprego-inserção, centros de emprego protegido e contratos de emprego apoiado em entidades empregadoras sob a forma de enclaves dentro da categoria de emprego apoiado.

Um dos principais objetivos da nova política de saúde mental é substituir os hospitais psiquiátricos por serviços baseados na comunidade, que permitam um tratamento de proximidade às populações e o desenvolvimento de serviços de reabilitação psicossocial num contexto verdadeiramente inclusivo. A resistência a tal mudança é, no entanto, ainda muito forte, sobretudo por uma parte significativa da classe médica, com grande influência institucional, que teme ver diminuído o poder de que sempre usufruiu com a instalação do novo paradigma de cuidados. Mas, de uma forma geral, todos os profissionais de saúde mental temem a nova abordagem pelas alterações de papéis e de funções que acarreta e que não se sentem preparados ou motivados para desempenhar.

Como vimos no capítulo 3, a capacidade de uma entidade para implementar intervenções de reabilitação psiquiátrica orientadas por uma visão de recuperação está relacionada com os conhecimentos e as atitudes dos profissionais (Farkas & Anthony, 2010).

De uma forma geral, no nosso país, a formação graduada e pós-graduada em diferentes áreas profissionais fornece treino insuficiente a nível da reabilitação psiquiátrica e dos cuidados de saúde mental orientados por um paradigma de recuperação (*recovery*).

No caso específico da Universidade de Coimbra, a licenciatura e mestrado integrado em Medicina integra apenas uma disciplina de psiquiatria e um estágio de saúde mental com duração de 4 semanas, com uma abordagem mínima da componente de reabilitação psiquiátrica. O foco predominante da especialidade em psiquiatria é o tratamento farmacológico da doença mental, que, apesar de fundamental, não é suficiente se pretendemos uma abordagem holística na avaliação e tratamento das doenças mentais.

A licenciatura e diversos mestrados em Psicologia não incluem formação, quer teórica quer prática, em reabilitação psiquiátrica. Note-se que a presente tese de Doutoramento é a primeira na Faculdade de Psicologia e de Ciências da Educação da Universidade de Coimbra a abordar esta problemática.

Nos Estados Unidos da América, os conselheiros de reabilitação (*rehabilitation counselors*) têm um papel crucial nesta área. A prática do aconselhamento na área da reabilitação é definida como um processo sistemático que auxilia as pessoas com incapacidades a atingir os seus objetivos pessoais, profissionais e de vida independente no contexto mais integrador possível, através do processo de aconselhamento. O processo de aconselhamento envolve comunicação, definição de metas, intervenções psicológicas, vocacionais, sociais, comportamentais e de promoção do ativismo (Commission on Rehabilitation Counselor Certification, 1994).

O aconselhamento de reabilitação é, assim, definido pelo auxílio das pessoas com incapacidades na adaptação ao meio ambiente, bem como pela promoção dos apoios no ambiente necessários à acomodação das necessidades do indivíduo. O aconselhamento de reabilitação tem por missão a plena participação das pessoas com incapacidades em todos os aspetos da sociedade, com especial ênfase na área do emprego (Szymanski, 1985). No nosso país, não existe ainda formação específica para conselheiros na área da reabilitação.

Em relação às atitudes dos profissionais, a prestação de cuidados orientados por uma visão de recuperação (*recovery*) envolve, em primeiro lugar, o valor da dignidade humana, que se verifica em acções tão simples como a utilização das mesmas casas de banho por profissionais e utentes, o que nem sempre acontece no nosso país (capítulo 3). Esta questão remete-nos para o capítulo 4 desta tese que explora o estigma nas suas diferentes facetas, inclusivamente da parte dos profissionais, como uma barreira à integração comunitária.

Apesar da literatura científica mostrar que o contato social com pessoas que sofrem de doenças mentais pode levar à diminuição do estigma, este facto não se aplica nem às famílias, nem aos profissionais. Se compreendemos que a família tem défices de conhecimento sobre a doença mental, levando a interpretações erróneas sobre o comportamento do familiar com doença mental, o estigma dos profissionais não pode ser atribuído a esse fator.

O facto é que níveis elevados de Emoção Expressa (comentários críticos, hostilidade, e sobre-proteção) são encontrados não só nas famílias, mas também nos profissionais (Willets & Leff 1997). Além disso, cerca de três quartos das publicações analisadas por Schulze (2007) mostram que as atitudes dos profissionais de saúde mental não divergem das atitudes da população geral, ou são ainda mais negativas.

Como vimos na revisão de literatura efetuada no capítulo 4, um pouco por todo o mundo, boa parte dos profissionais são cépticos em relação à possibilidade de tratamento e reabilitação das pessoas com esquizofrenia. Alguns profissionais consideram que as pessoas com doença mental não devem casar e outros acreditam que estas precisam da mesma forma de controlo que uma criança.

Os profissionais de saúde mental subestimam as competências das pessoas com doença mental (Rinaldi et al., 2008) e a sua capacidade para fazer escolhas. As atitudes negativas dos profissionais, que envolvem baixas expetativas em relação às pessoas que utilizam os serviços de saúde mental, são, ainda que inadvertidamente, destruidoras de sonhos. As pessoas com doença mental, como todas as pessoas em geral, precisam de alguém que acredite nelas, quando elas próprias não conseguem acreditar em si mesmas. Quando tal não acontece acabam por interiorizar o estigma de que são alvo, dando origem ao chamado auto-estigma (*self-stigma*), caracterizado por sentimentos de inadequação e baixa auto-confiança.

Esta situação não é rara no nosso país e os profissionais, subestimando a capacidade das pessoas com doença mental para fazer escolhas, acabam, muitas vezes, por atribuir-lhes um papel passivo no processo de tratamento e reabilitação. Como demonstrado no capítulo 3, o julgamento dos profissionais, caracterizado por medo e baixas expetativas, frequentemente prevalece nos processos de tomada de decisão e a participação das pessoas com doença mental no planeamento dos seus cuidados é, muitas vezes, minimizada.

Além disso, a supremacia, no nosso país, de programas de reabilitação psicossocial em contextos segregados e protegidos pode ser explicada, pelo menos em parte, pelas baixas expetativas dos profissionais em relação às pessoas com doença mental. O estudo de Marques, Queirós e Rocha (2006), realizado em treze instituições portuguesas, demonstrou que as pessoas com doença mental acreditam mais do que os profissionais que o emprego competitivo é viável.

Estas atitudes dos profissionais são fruto de uma formação baseada num paradigma de cuidados caracterizado por uma abordagem paternalista em contextos altamente protegidos. Mas é importante questionar: como é possível os profissionais de saúde mental serem ativistas da luta contra o estigma, quando eles próprios estigmatizam as pessoas com doença mental?

Um dos maiores desafios para a mudança de paradigma em saúde mental é, portanto, contribuir para que os profissionais mudem as suas atitudes de forma a que estas se coadunem com a nova filosofia de cuidados, reconhecendo que profissionais, utilizadores de serviço e cuidadores informais têm o mesmo estatuto. Assim, é importante que os profissionais, quer de aconselhamento, quer todos os que lidam na sua prática diária com pessoas com doença mental, percebam que a luta contra o estigma da doença mental começa neles mesmos e com a consciência dos seus próprios comportamentos discriminatórios. É crucial que os profissionais evitem a separação “nós” e “eles”.

Por outro lado, é fundamental que o processo de aconselhamento pessoal e vocacional foque as forças e capacidades da pessoa com doença mental, ao invés dos seus défices. A doença mental cria um sentimento de ser diferente dos outros, pelo que processos de avaliação e estratégias de intervenção focados nos défices vão reforçar a identidade estigmatizada. Assim, e de acordo com Slade (2012), a mudança fundamental num sistema de cuidados orientado por uma visão de recuperação envolve ver o utilizador dos serviços como uma pessoa e não como um paciente (alguém que é fundamentalmente diferente). É urgente que os profissionais abordem o utilizador de serviços como uma pessoa cujos esforços para viver uma vida com significado e propósito são fundamentalmente semelhantes àquelas que não têm doença mental (Slade, 2012).

Desta forma, os profissionais devem guiar a sua prática tendo em conta que as pessoas com doença mental têm as mesmas aspirações que as pessoas sem doença mental: ter uma vida "normal", satisfatória e com significado. As pessoas com doença mental têm, geralmente, os mesmos objetivos das outras pessoas: ter um emprego, habitação decente, onde a sua privacidade é assegurada, ter relações afetivas, uma rede de suporte social, e atividades de lazer. Assim, como defende Slade (2012) a maior contribuição dos serviços de saúde mental para a recuperação das pessoas com doença mental é apoiar soluções comuns para problemas humanos comuns.

Não importa apenas o que fazem os profissionais, mas também e sobretudo o modo como o fazem. Por conseguinte, a forma como os profissionais se relacionam com os utilizadores de serviços é um fator crucial na sua recuperação. A implementação de serviços e intervenções orientados por uma visão de *recovery* pressupõe criar uma cultura de envolvimento dos utentes, o que implica uma forte parceria entre profissionais e os utilizadores de serviços. É indispensável assegurar que o planeamento dos cuidados seja baseado nos valores da pessoa com doença mental, nas suas preferências em relação ao tratamento, nas suas forças e objetivos pessoais (Bird, Leamy, Le Boutillier, Williams, & Slade, 2011). Enquanto decisões acerca da medicação podem ser compartilhadas, aspetos como habitação e carreira são profundamente pessoais, cabendo ao profissional, nomeadamente ao profissional de aconselhamento, apoiar na exploração das várias alternativas existentes para o alcance dos objetivos da pessoa com experiência de doença mental. Por um lado, é fundamental que a pessoa em reabilitação perceba que pode escolher e, por outro, é importante que os profissionais percebam que as pessoas com problemas de saúde mental têm poder de decidir sobre as suas vidas.

Segundo Bird e colaboradores (Bird et al., 2011) são três os valores e objetivos pelos quais os serviços de saúde mental devem orientar as suas atividades numa perspetiva de recuperação. 1) O primeiro e principal objetivo dos serviços de saúde mental é apoiar o esforço de recuperação pessoal (*personal recovery*): quer o tratamento, quer a reabilitação podem ser importantes contribuições para alcançar este objetivo, mas são meios e não fins; 2) o trabalho dos profissionais deve estar focado nos objetivos da pessoa que utiliza o serviço; 3) os serviços de saúde mental trabalham tendo em conta que as pessoas são ou serão (quando em crise) responsáveis pelas suas próprias vidas.

Assim, e no que diz respeito particularmente à reabilitação, não é suficiente providenciar abrigo, trabalho ou cursos de formação para as pessoas com doença mental. É fundamental perceber se essas medidas se enquadram naquilo que são os valores e objetivos da pessoa com doença mental. E talvez esta seja a grande lacuna ainda existente em Portugal: uma maior preocupação com os serviços do que com as pessoas que os utilizam. A reabilitação psicossocial deve sempre assentar numa visão de recuperação, ou seja, promover as condições pessoais para uma vida com significado, mais do que simplesmente apoiar a adaptação e a sobrevivência na comunidade (Farkas, 2007).

Intervenções baseadas nos valores da recuperação (*recovery*) são fundamentais na prestação de serviços que garantam o respeito pela liberdade e dignidade humanas. Os contextos segregadores, ainda muito frequentes no nosso país, opõem o princípio da recuperação, o qual, ao invés de restringir as pessoas com doença mental a guetos, implica promover papéis valorizados fora dos contextos dos serviços de saúde mental (Farkas, 2007). Infelizmente, a reabilitação psicossocial em Portugal não tem acompanhado os mais recentes avanços da área reportados na literatura internacional.

Formulações conclusivas e prospectivas

Pela multiplicidade e complexidade das questões debatidas e dos dados analisados nos diversos estudos que integram a presente dissertação, torna-se praticamente impossível proceder a um resumo e formular uma conclusão. Ousamos, todavia num esforço de síntese, apresentar um conjunto de formulações em jeito de conclusões que revestem na sua maioria uma dimensão prospectiva de recomendação ou orientação para uma concretização num futuro próximo tendo em vista o desenvolvimento da reabilitação psicossocial/psiquiátrica em Portugal. De entre elas, destacamos como essenciais as seguintes:

1) Incentivar a implementação de programas de reabilitação baseados em evidência;

2) Criar uma legislação baseada na mais atual evidência científica e nas recomendações internacionais para a reabilitação psicossocial de pessoas com doença mental severa;

3) Promover a investigação científica nesta área e desenvolver uma cultura de avaliação de serviços, que demonstre o cumprimento dos objetivos a que se destinam.

4) Criar módulos de reabilitação psiquiátrica e recuperação nos currículos dos cursos das diversas áreas profissionais da saúde;

5) Criar cursos de pós-graduação em reabilitação psiquiátrica e formar conselheiros de reabilitação;

6) Combater o estigma da doença mental em diferentes frentes: população geral, família, profissionais, empregadores, auto-estigma e ainda o estigma por associação;

7) Promover a mudança de atitudes dos profissionais, nomeadamente no que diz respeito à diminuição do estigma e ao estabelecimento de relações de parceria com os utilizadores dos serviços que instiguem esperança e favoreçam a auto-determinação;

8) Promover uma abordagem de reabilitação baseada numa visão de recuperação, tendo como objetivo não só a melhoria do funcionamento, mas também, e sobretudo, a satisfação nos papéis desempenhados e a perceção de vida com significado.

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