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An independent academic psychologist, based in England, who has written extensively on different areas of psychology with an emphasis on the critical stance towards traditional ideas.

A complete listing of his writings at <http://kmbpsychology.jottit.com>.

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# **1. RECOVERY, SERVICE USER INVOLVEMENT, STIGMA AND "MENTAL HEALTH"**

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## **1. INTRODUCTION**

Beresford (2002) argued that the philosophical underpinnings of mental health have "remained so long glued to their nineteenth century origins". Sadly, he pointed out: "The increasing association of mental health service users with 'dangerousness' and the constant coupling of cruel and murderous activities with 'mental illness', as though 'bad' is tantamount to mad, is a defining feature of early twenty-first century discussion" (Beresford 2002 p581).

## **2. RECOVERY**

Recovery in a mental health context can refer to a remission or improvement of symptoms (clinical view) or, from the subjective perspective, "a process of personal growth and development, regaining control, and a meaningful life with or despite a psychiatric disorder" (Jaeger and Hoff 2012)<sup>1</sup>. The latter focus includes hope, self-identity, meaning in life, and personal responsibility (Andresen et al 2003).

Leamy et al (2011) distinguished the categories of recovery journey (13 items - eg: active, unique, gradual), recovery processes (measurable dimensions of change), and recovery stages (framework for clinical intervention) (Jaeger and Hoff 2012).

Whitley and Drake (2010) outlined five dimensions of personal recovery - clinical (control of symptoms), existential (eg: hope, empowerment), functional (eg: in relation to employment), physical (general health and

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<sup>1</sup> A critical approach to mental health may ask recovery from what as the classification of mental illness is historically a fluid process (appendix A).

well-being), and social (eg: social interactions).

Burgess et al (2011) collected 33 instruments to measure recovery, of which 22 measured an individual's recovery (table 1) and 11 the recovery orientation of services (table 2) (but not both).

Burgess et al (2011) specified criteria for assessing the usefulness of the instrument:

- Measure explicitly domains related to recovery - eg: feelings of hopelessness.
- Is relatively short (less than 50 questions) and easy to use.
- Gives quantitative data.
- Demonstrates psychometric properties like reliability and validity.

Recovery Assessment Scale (RAS) (Giffort et al 1995)

41 items (shorter version 24 items); eg: "I have a desire to succeed", and "I can handle it if I get sick again"; responses on 5-point Likert scale (1 = strongly disagree, 5 = strongly agree).

Five domains:

- personal confidence and hope
- willingness to ask for help
- goal and success orientation
- reliance on others
- no domination of symptoms

Stages of Recovery Instrument (STORI) (Andresen et al 2006)

50 items; eg: "I feel as though I don't know who I am any more", "I have recently begun to recognise a part of me that is not affected by the illness", and "I am learning new things about myself as I work towards recovery"; responses on 6-pt Likert scale.

Stages of recovery:

- 1. Moratorium: A time of withdrawal characterised by a profound sense of loss and hopelessness.
- 2. Awareness: Realization that all is not lost, and that a fulfilling life is possible.
- 3. Preparation: Taking stock of strengths and weaknesses regarding recovery, and starting to work on developing recovery skills.
- 4. Rebuilding: Actively working towards a positive identity, setting meaningful goals and taking control of one's life.
- 5. Growth: Living a full and meaningful life, characterised by self-management of the illness, resilience and a positive sense of self (Andresen et al 2006 p972).

Table 1 - Two examples of instruments to measure personal recovery.

Recovery Oriented Systems Indicators Measure (ROSI) (Dumont et al 2005)

Assesses recovery orientation of a mental health system by examining the factors which aid and hinder recovery using two data sources:

- Adult Consumer Self-Report Survey - 42 items (eg: "There is at least one person who believes in me", "Staff respect me as a whole person") examining domains like self-care and wellness, staff treatment and knowledge.
- Administrative Data Profile - 23 items (eg: "Staff see me as an equal partner in my treatment program, "There was a consumer peer advocate to turn to when I needed one") on domains like peer support, coercion, and staffing ratios.

Table 2 - Example of instrument to measure recovery orientation of services.

Asking patients, clients, service users, customers, consumers, or survivors of the mental health system (depending which term is used) about their treatment success is called a number of different things including patient-reported outcomes (PROs), patient-reported outcome measures (PROMs), self-rated outcomes, or subjective evaluation criteria (Reininghaus and Priebe 2012). These terms refer to concepts like treatment satisfaction, subjective quality of life, needs for care, and quality of therapeutic relationship (Reininghaus and Priebe 2012).

Reininghaus and Priebe (2012) performed a literature review of PROs for individuals with psychosis.

Crawford et al (2011) asked an "expert group" of 25 service users in the UK with mood disorders and/or psychosis to evaluate twenty-four widely used outcome measures for treatment. Each measure was scored on an eleven-point Likert scale for its appropriateness. The highest scoring measures were the Liverpool University Neuroleptic Side Effect (LUNSERS), the World Health Organisation - Quality of Life (WHO-QOL), and the Warwick-Edinburgh Well-being Scale (WEWS).

The service users preferred self-rated measures (rather than clinician-rated), those that captured the negative effects of treatment, and disliked criteria for a "good" outcome (eg: better social functioning)<sup>2</sup>. Some of the measures used most commonly by clinicians received

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<sup>2</sup> "For instance, some group members expressed the view that it should not be assumed that people who got on well with family members had better social functioning, because some people made a conscious choice not to have contact with family members. Some group members considered it inappropriate that measures were grounded in judgements about which aspects of relationships with others or ways that people spend their time indicated a 'better' outcome. Group members suggested, instead, that people should be asked whether people were happy with these aspects of their lives" (Crawford et al 2011 p341).

the lowest ratings (eg: Global Assessment of Functioning; GAF).

In the different vein, the McGill Illness Narrative Interview (MINI) (Groleau et al 2006) was developed to understand the subjective experience and meaning to the individual of a disease, illness or symptom (physical or mental). It has 46 questions divided into five sections:

1. Initial illness narrative - eg: "If you went to see a doctor, tell us about your visit to the doctor/hospitalisation and about what happened afterwards".

2. Prototype narrative - eg: "In what ways do you consider your [health problem] to be similar to or different from another person's health problem".

3. Explanatory model narrative - eg: "Do you have another term or expression that describes your [health problem]?".

4. Services and response to treatment - eg: "What made that treatment difficult to follow or work properly?".

5. Impact on life - eg: "How has your [health problem] changed the way you live?".

Dowbiggin (2011), in a history of the "quest for mental health", described the "ever-widening democratisation" of mental healthcare with deinstitutionalisation and the growth of patients' rights groups as positive, while at the same time leading to a focus on the "worried well" who demand the right to "emotional well-being" from their governments. "Dowbiggin views these developments darkly, as leading not to greater freedoms, but to renewed oppression and servitude of the new 'psychological man' under the yoke of 'emotional conformism'. By Dowbiggin's account, today's 'patients' seem to be even more enslaved than their institutionalised forebears" (Engstrom 2012 p487).

Less than half of individuals with major depressive disorder (MDD) experience improvement of symptoms with the first anti-depressant prescribed (Tansey et al 2012). This has led to interest in why some individuals benefit from some anti-depressants and not other individuals or anti-depressants. One possible answer is genetic differences between individuals ("genetic determinants of anti-depressant response"; Tansey et al 2012). Such knowledge would allow a more personalised treatment that prescribes the best anti-depressant for an individual.

Unfortunately, Tansey et al (2012) found no single

common genetic variant (out of more than 500 000 genetic markers) that predicted response to selective serotonin reuptake inhibitor (SSRI) or selective noradrenaline reuptake inhibitor (SNRI) anti-depressants. They used the data from the NEWMEDS consortium <sup>3</sup>, of which three studies of anti-depressants in Europe. This gave a total sample of 2146 adults with self-reported White European ancestry diagnosed with unipolar MDD (using DSM-IV criteria).

### 3. SERVICE USER INVOLVEMENT

"User involvement" is a term to describe the participation of individuals who have experienced the mental health system in decision-making about the mental health system <sup>4</sup>.

The concept of service users as active in the research of service users is not dissimilar to other fields - for example, "for research on women to be undertaken by women, research on particular disabilities to be undertaken by people experiencing those disabilities, and for research to be undertaken by people from black and minority ethnic communities where the research involves their community" (Telford and Faulkner 2004 pp549-550).

Psychiatry is dominated by the idea of "evidence-based medicine", which seeks to use scientific knowledge to establish the best practice, but it can mean that "patients are left feeling that their concerns are forgotten and that they are little more than a disease being treated" (Faulkner and Thomas 2002). On the side of psychiatry, "there is a political resistance to seeing psychiatric patients as experts and to their involvement as partners in helping to set research agendas, coupled with a dominance of clinical neuroscience in the psychiatric and allied journals" (Faulkner and Thomas 2002) <sup>5</sup>.

Telford and Faulkner (2004) distinguished between user-led/user-controlled research, and user involvement

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<sup>3</sup> Novel Methods leading to New Medications in Depression and Schizophrenia (<http://newmeds-europe.com/>)

<sup>4</sup> For example, the World Health Organisation Regional Office for Europe announced a mental health strategy in March 2011 which would involve service users and their families in its development (Callard and Rose 2012).

<sup>5</sup> "The gold standard of scientific respectability in health service research - and the standard upon which evidence is evaluated - is the randomised controlled trial. This may be the accepted way of answering the question 'which is the effective treatment for condition X?', but people are complex subjects for investigative methods that befit the natural sciences... Clinical effectiveness, if restricted to the narrow definition of 'symptom relief', may fail to take into account relevant aspects of people's lives, aspects that may be crucial in determining an individual's decision to continue treatment, remain in contact with services or indeed survive" (Faulkner and Thomas 2002 p2).

in research (collaborative research). In the latter case, a number of motives for involvement have been proposed:

- Frustration with clinical academic research.
- Promoting the value of expertise by experience.
- Seeking change and improvements.
- Asking different questions and getting different answers (to academic researchers).
- Questioning the independence of services and professionals.
- Challenging models of understanding.
- Developing skills, confidence and empowerment (Telford and Faulkner 2004 p551).

There are also barriers to user involvement in collaborative research, including practical issues like cost or finding the "right type" of service user <sup>6</sup>, attitudes of researchers (eg: "active doctor - patient passive"), concern over the "impaired state" of service users, and the desire for the research to be "objective" (where service users are viewed as "subjective") (Telford and Faulkner 2004).

Rose (2003) listed two ways that as a service user she had experienced problems with academics and clinicians in collaboration projects - they "simply regard the person as somebody's (a potential?) patient", and the "user status may be used to undermine one's opinion, as it is held that a person cannot be both logical and mad".

Simpson and House (2003) listed the following barriers:

- Questioning whether user involved are representative.
- Lack of interest from users.
- Tokenism (giving users trivial tasks to do).
- Concern about users' ability to be rational.
- Stress of involvement for users.
- Users' lack of experience.
- Communication barriers (eg: academic jargon).

Thornicroft et al (2002) observed that "service users' priorities for research are not the same as those of professionals and funding bodies". Forty service users of the South London and Maudsley NHS Trust were asked for their research priorities. The top three choices were "user involvement in all stages of the research process", "discrimination and abuse", and "social/welfare issues".

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<sup>6</sup> Telford and Faulkner (2004) observed: "Researchers may express concerns about the 'representativeness' of service users..., but remain silent about the 'representativeness' of researchers" (p554).

"New treatments", for example, was rated as unimportant (Thornicroft et al 2002).

Faulkner (2000) reported a study involving, and run by 71 service users, which found that relationships with others and peer support were key to these individuals.

Trivedi and Wykes (2002) described a joint research project between service users and academic researchers. The users placed more emphasis on how the intervention was delivered in a study of the effects of group medication education sessions with psychiatric in-patients. But user involvement added time and cost for consultation to the research project. Trivedi and Wykes (2002) admitted that the "commitment to collaboration will be demanding of the research team too as its members come to terms with the competing objectives".

Service users are often interviewed about their experiences and what changes they would want to the mental health system. If the interviewer is also a service user, it can be both positive and negative. Bengtsson-Tops and Svensson (2010) talked to seventeen services users in Sweden who had been interviewed by other service users. From analysis of their interviews, Bengtsson-Tops and Svensson (2010) picked out four main themes:

i) "Being interviewed by a user was experienced as something special".

ii) "The interview was experienced as a dialogue between two equals who shared the same world of being a patient in psychiatric care. In an atmosphere of comradeship both parts co-operated and private opinions and experiences were shared. The interviewer was perceived as keen and listening and as a friend or an old acquaintance that it was easy to get on well with" (Bengtsson-Tops and Svensson 2010 p237).

iii) "On the other side being interviewed by another user was also experienced as uncertain and insecure, mainly in relation to issues of secrecy and confidentiality. For example, the informants worried about whether information would leak to staff or users in the psychiatric support system. Additional, feelings of uncertainty could be related to distrust of users in general. The lack of confidence could be due to anxiety aroused by experiences of in-patient care where the patients have behaved strangely (Bengtsson-Tops and Svensson 2010 p238).

iv) Ambivalence about aspects of the research project - eg: more willing to consent to an interview with another user versus refusal to participate if user-interviewer lived in small village. One participant told

Bengtsson-Tops and Svensson (2010): "Even if he has to maintain professional secrecy he might perhaps let something slip to his tongue to somebody, like, I don't know. It's a bit ambiguous, that. Well, maybe some other association or when they meet in the network or something like that? It's just that, if you know users, they're not like that. Sometimes they may forget about secrecy. I don't know. That's the feeling I get" (p239).

Or in relation to the user-interviewer - eg: happier to talk about issues to fellow sufferer versus unsure about burdening them with details of own story of suffering.

Simpson and House (2002) found twelve studies published between 1966 and 2001 that compared projects involving or not service users. Mental health services that employed service users had greater satisfaction with personal circumstances and less hospitalisation by its clients, but were less satisfied with services when interviewed by other service users. For example, as case managers, service users spent longer in face-to-face contact with their clients, but did less office work, and had a higher turnover rate. Employing service users with a history of serious mental health problems needed adequate support. Simpson and House (2002) concluded from their review: "Users can be involved as employees, trainers, or researchers without detrimental effect. Involving users with severe mental disorders in the delivery and evaluation of services is feasible".

Trivedi and Wykes (2002) proposed ten questions for researchers to ask before user involvement in planning joint research:

- What is the value of user involvement?
- How will users be involved in the research process?
- What projects might be suitable for user involvement?
- What proposal will be prepared for presentation to users?
- How will the initial approach be made to users?
- How will users' responses be considered?
- Will research partnerships with users be formalised?
- How will the proposal be jointly assessed?
- How will the project be written up?
- How will dissemination occur?

### **3.1. Listening to Service Users About Physical Health**

Individuals diagnosed with a mental disorder often have physical health problems as well, and/or have greater health risks (eg: twice as likely as general population to die from coronary heart disease) (Chadwick

et al 2012).

Studies have also shown that individuals with mental disorders have problems accessing physical healthcare services. The reasons given include lack of awareness and knowledge of services, communication problems with healthcare staff, stigma, and poverty on the side of the individuals, while the staff may lack knowledge to help among other reasons. There is also "diagnostic overshadowing" where the focus is upon the mental health problems to the detriment of physical health problems. Very little of this information has come from asking the sufferers themselves (Chadwick et al 2012).

Chadwick et al (2012) found three quantitative and six qualitative studies in English between 2000 and 2011 that asked mental health service users about barriers to the use of physical healthcare services. The majority of them were undertaken in the USA (seven studies) with one study in the UK and one in Australia.

The study in the UK (Lester et al 2005) involved eighteen focus groups of 5-12 individuals (both mental health services users and healthcare staff). Barriers to the use of physical health services included practical issues like noisy or crowded waiting rooms as well as lack of confidence, the effect of the mental illness, and the perception that mentally healthy individuals had priority. The health professionals admitted that they found it difficult to communicate with individuals with serious mental disorders. Both groups of participants were aware of "diagnostic overshadowing" (though that term may not have been used).

Table 3 summarises the barriers to use of physical health services as reported in studies found by Chadwick et al (2012).

Specific issues related to individuals with mental disorders:

- Lack of awareness of help and services (eg: screening programmes).
- Lack of understanding/education.
- Communication problems with staff.
- Stigma.
- Discrimination.
- Lack of confidence about using services.
- Effects of mental disorder.
- Fear of being turned away or accused of faking.
- Fear of professionals.

Issues common to other groups in society:

- Long waiting times.
- Poverty.
- Homelessness.
- Social isolation.
- Poor diet/lifestyle.
- Atmosphere of service (eg: waiting room crowded; feeling hurried).
- Lack of medical insurance (in USA)/cost.
- Lack of services in deprived areas.
- Practical issues like time and transport.

- Problems navigating services/system.

Issues related to healthcare professionals:

- Lack of skill to deal with such individuals.
- Lack of awareness of their physical health needs.
- Attitude/lack of caring behaviour/disrespectful.
- Diagnostic overshadowing.

Table 3 - Barriers to physical health service use by individuals with mental disorders.

#### 4. STIGMA

The ability to live and recover from mental health problems can be influenced by stigmatisation - "the expression of a discrediting stereotype deriving from falsely assumed associations between a group of people and unfavourable characteristics, attributes or behaviours" (Anselm et al 2012). The consequences include reduced self-esteem and quality of life. "Courtesy-stigma" is where those close to the stigma target are also stigmatised (Anselm et al 2012) (eg: three-quarters of parents of children with attention deficit hyperactivity disorder (ADHD) in one study; dosReis et al 2010).

Public stigma is a worldwide phenomenon which persists over time (despite increases in public knowledge about mental illness) (Evans-Lacko et al 2013). Mehta et al (2009) reported a worsening of attitudes in England between 2000 and 2003. Attitudes were measured each year with items like "One of the main causes of mental illness is a lack of self-discipline and will-power", "There is something about people with mental illness that makes it easy to tell them from normal people" and "Virtually anyone can become mentally ill". There was a significant decline on 17 of the 25 items and no improvements.

Stigma has been studied and found in relation to ADHD. For example, undergraduates gave more socially-negative ratings to an adult with ADHD than with a medical condition (eg: asthma) or an "ambiguous weakness" (eg: perfectionist) (Cann et al 2008).

Anselm et al (2012) developed a questionnaire to measure stigma towards adults with ADHD. Initially, sixty-four items (with a six-point Likert scale) were presented to 1261 respondents in the Netherlands. Then factor analysis was used to distinguish six factors and 37 items. These factors were:

i) Reliability and social functioning (9 items) - This factor characterised the perceptions of ADHD sufferers as unreliable and self-focused, which manifest in relationship problems (eg: "Under medication, adults with ADHD are less trustworthy"; "Adults with ADHD are

self-focused and egoistic").

ii) Malingering and misuse of medication (9) - The belief that individual's may simulate symptoms to get medication which is marketed by pharmaceutical companies (eg: "Many adults with ADHD simulate symptoms"; "Adults with ADHD lie more often than adults with ADHD").

iii) Ability to take responsibility (5) - This related views about a sufferer's ability to take responsibility (eg: "I would mind if my investment advisor had ADHD"; "I would mind if the teacher of my children had ADHD").

iv) Norm violating and externalising behaviour (5) - The belief that sufferers act without thinking (eg: "Adults with ADHD cannot deal with money"; "Adults with ADHD act without thinking").

v) Consequences of diagnostic disclosure (5) - This factor covers the negative self-image of sufferers who have to disclose their diagnostic status to others (eg: "Adults with ADHD are lower social status"; "Adults with ADHD feel excluded from society").

vi) Etiology (4) - Beliefs about behaviours associated with ADHD (eg: "ADHD is caused by bad parenthood"; "Extensive exposure to video games and TV shows can cause ADHD").

#### **4.1. Wesselmann et al (2012)**

Individuals are more likely to make a negative judgment about an individual with mental illness if there is time pressure to make the decision. Wesselmann et al (2012) showed 145 US undergraduates (103 of them female) a short video about a student called "Harry" visiting an office of a dentist or a psychiatrist. This was the first independent variable - whether he was inferred to suffer from mental illness or not. The video also showed Harry at a party where he behaves ambiguously towards his friend, either slapping the friend's hand or shoving him. This is the second independent variable - the type of behaviour towards the friend (aggressive or not). Then the participants rated Harry on several adjectives (eg: friendly, mean, aggressive) and his perceived dangerousness (eg: "I would feel unsafe about Harry"). All the ratings used a five-point Likert scale. These ratings were the dependent variable measures. There was also a third independent variable, which was the time allowed to complete the ratings - five seconds (quick response condition) or 20 seconds (delayed response

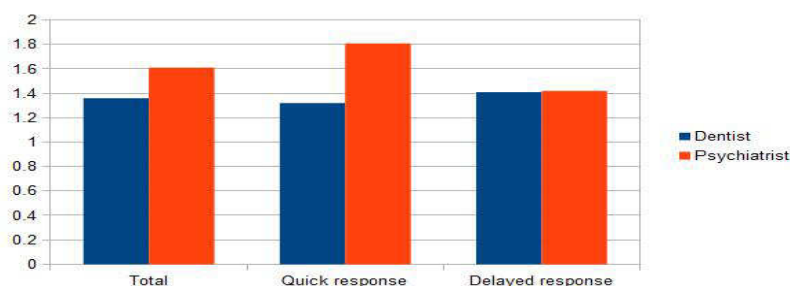
condition)<sup>7</sup>. Altogether there were eight independent conditions (table 4).

	Quick Response	Delayed Response
Dentist/shove	1	5
Dentist/slap	2	6
Psychiatrist/shove	3	7
Psychiatrist/slap	4	8

Table 4 - Eight conditions in Wesselmann et al's (2012) Study 1.

The researchers hypothesised "that participants forced to make their ratings quickly would be more likely to perceive Harry as dangerous when he had seen a psychiatrist compared to when he had seen a dentist. In contrast, we expected that participants who were instructed to take more time to make their ratings would not show this difference" (Wesselmann et al 2012 p566). It is a one-tailed hypothesis (because it predicts the direction of the difference).

The participants perceived Harry as more dangerous when he visited a psychiatrist than a dentist (conditions 1, 2, 5 and 6 vs 3, 4, 7, and 8 in table 4) ( $p < 0.01$ ), but this difference was exacerbated in the quick response condition ( $p < 0.01$ ) (figure 1)<sup>8</sup>.



(Data from Wesselmann et al 2012 table 1 p567)

Figure 1 - Mean rating of dangerousness (out of 5) in Study 1.

<sup>7</sup> About these times, Wesselmann et al (2012) stated: "We chose 5 s as the interval for our time pressure condition because pilot testing indicated it allowed enough time for participants to adequately respond to each question yet still be within the range utilised by previous research using similar manipulations... We chose 20 s to be the interval for our non-pressure condition because previous research suggests that automatic processes may still have a prominent influence on attitudes for as long as 10 s...; we wanted to give participants ample time to make their decisions without feeling rushed.." (p566).

<sup>8</sup> The mean difference between slap and shove conditions was not significant (2.49 vs 2.33).

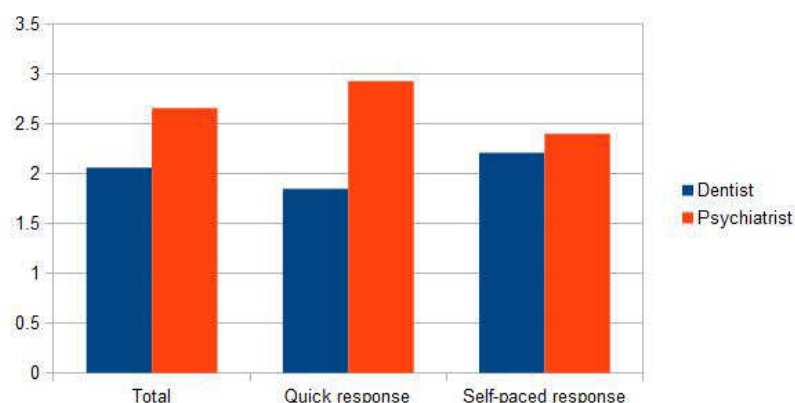
But all the mean ratings were relatively low. So in their second experiment, Wessellmann et al (2012) changed two elements of the design. Participants saw a video of Harry visiting either a dentist because he had dental problems (control) or a psychiatrist because he suffers from schizophrenia (table 5) (first independent variable). The second independent variable of time to complete the ratings was four seconds or no time limit (self-paced). Ninety-four female undergraduates were randomly divided into four independent groups.

- Dentist: You will now see a picture of a man named Harry. Harry was diagnosed as having a severe dental problem. Because of this problem Harry went to see his dentist. This picture shows Harry with his dentist.
- Schizophrenia: Now you will see a picture of a man named Harry. Harry was diagnosed with schizophrenia, which is a severe mental illness. Schizophrenia is a mental disorder that lasts for at least six months, with active symptoms that persist for at least one month. Some of the symptoms of schizophrenia during its active stage are delusions, hallucinations, disorganized speech, and catatonic (or rigid) motor behaviour. Because of this diagnosis of schizophrenia, Harry went to see his psychiatrist. This picture shows Harry with his psychiatrist.

(Source: Wessellmann et al 2012 p568)

Table 5 - Narrative of videos in Study 2.

Participants were significantly more likely to rate Harry visiting the psychiatrist as dangerous in the quick response condition than the dentist ( $p < 0.01$ ), while there was no significant difference in the ratings in the self-paced conditions (figure 2).



(Data from Wessellmann et al 2012 table 2 p569)

Figure 2 - Mean rating of dangerousness (out of 5) in Study 2.

Wesselmann et al (2012) concluded: "We demonstrated in two experimental studies that participants were more likely to stigmatise a person with mental illness when their ability to control their reactions was reduced by time pressure compared to when their ability was not hindered" (p569).

#### Evaluation

i) The majority of participants were female. Other research is ambiguous about whether men's and women's attitudes towards mental illness differ (Wesselmann et al 2012).

ii) The stimulus character was male. Other research suggests that a woman with mental illness is perceived as less dangerous than a man. Wesselmann et al (2012) admitted: "We suspect that the sex of the stimulus person would not influence how time pressure affects stigma endorsement in general but might influence the overall magnitude" (p569).

iii) Viewing a short video is different from meeting an individual in real-life. This is a challenge to the ecological validity of the experiments (ie: their applicability to real-life).

iv) All the participants were undergraduates in the USA (probably at Illinois State University) (who are not representative of the general population).

v) Asking the participants directly about the dangerousness of Harry gives them clues as to the purpose of the research. This allows for the possibility of "demand characteristics", where participants behave the way they think the experimenter wants them to behave. Or the opposite ("screw you effect"), rather than how they would naturally behave. An indirect measure of the attitudes towards Harry might avoid this risk (eg: an task that appears different but is actually measuring the perceived dangerousness of Harry).

vi) In both studies the rating of dangerousness in the mental illness conditions was near the mid-point (overall mean for psychiatrist in Study 1 was 1.61 and 2.66 in Study 2). This could be a product of a five-point response scale (instead of seven or nine, for example).

vii) Independent participants (where participants do only one condition) was the best design for the experiments. The alternative of repeated measures, where all participants do all conditions was not sensible (eg: seeing both versions of the videos would make the purpose

of the experiment very obvious).

viii) No details were given of the sampling method. The students may have been volunteers or "course volunteers". In the latter case, they are offered course credits for participating, for example. In other words, it is too attractive to refuse or there is indirect pressure to participate (eg: fear that teacher may notice unwillingness to participate and mark coursework lower).

ix) In Study 2 the narratives about the visit to the dentist and the psychiatrist are noticeably different (table 5), which could have been a confounding variable.

#### **4.2. Stigma in Military**

Mental health problems may be stigmatised in society, but seeking treatment is stigmatised even more in the military. It is perceived as "weak" and violates the group norms of the military (Hipes 2012).

Hipes (2012) explored the perceptions of 563 US army personnel using four vignettes about a male soldier ("SPC Thompson") seeking treatment for insomnia and stress. The experiment compared the responses to seeking treatment for group cohesion (table 6) or individual medical reasons (first independent variable), and as a member of the participant's platoon or different (second independent variable). The perceived strength of Thompson was rated from 0 to 9 (with a higher score indicating greater strength). The experiment was an independent groups design.

- You are deployed to Afghanistan. Specialist Thompson, who is a member of your platoon, is considering seeking psychological treatment. For the past two months he has not slept well and has suffered from nightmares and high stress. He feels that his platoon will benefit from the treatment because he will be more alert on group missions and will be able to communicate more effectively with team members. In order to seek treatment, he will have to travel to another base, which requires him to miss two days of work with your platoon.

(Source: Hipes 2012 appendix B)

Table 6 - Vignette based on own platoon and group benefits from treatment.

It was predicted that Thompson would be perceived as weaker in relation to the first independent variable if seeking help for individual reasons. The findings were not significant. This was the same for the second independent variable, where it was hypothesised that seeking help would be rated as weaker in another platoon.

Hipes (2012) added a third variable to the analysis - having had contact with a close friend or family member (military or non-military) who sought help for mental health problems. Thompson was rated as significantly stronger by participants with contact compared to no contact.

#### **4.3. Anti-Stigma Programmes**

Anti-stigma programmes have been tried in a small number of countries. For example, "Like Minds, Like Mine" was started in New Zealand in 1996 with the aim of educating print media staff about how they represented individuals with mental illness. Over the following years, there was found to be a decrease in negative reporting and an increase in positive reporting of mental health issues (Mental Health Commission 2005).

In England, "Changing Minds" ran by the Royal College of Psychiatrists between 1998 and 2003 (Crisp et al 2004) <sup>9</sup> with limited success in changing media coverage (eg: Mehta et al 2009).

In 2002, the "see me" programme in Scotland used volunteers and partners to provide comments and articles on the experience of mental health problems (Dunion and Gordon 2005). The success in breaking the media presented link between schizophrenia and dangerous was claimed (Knifton and Quinn 2008), but disputed (Clement and Foster 2008 <sup>10</sup>).

The "Time to Change" (TTC) programme was launched in 2009 in England to reduce stigma and discrimination related to mental health problems (Henderson and Thornicroft 2009) <sup>11</sup>. One of the aims was to encourage positive press coverage of individuals with mental disorders.

Thornicroft et al (2013) evaluated the success of TTC by sampling newspaper reports of "mental health" stories from 2008 (before the programme) to 2011. They were looking for an increase in positive stories (eg: mental health promotion, experiences of sufferers themselves) and a decrease in stigmatising (eg: danger to others) and negative stories (eg: pejorative language).

Twenty-seven local and national English newspapers <sup>12</sup>

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<sup>9</sup> This included a two-minute film, "1 in 4", shown in cinemas, an electronic book called "Every Family in the Land", and "Reading Lights" picture books for 4-7 year-olds.

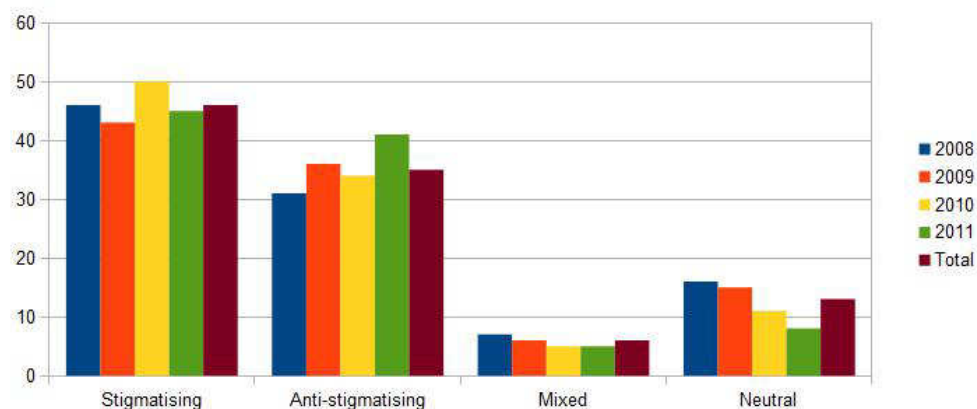
<sup>10</sup> This study showed no difference in the association of schizophrenia and violence in five UK national newspapers in 1996 and 2005.

<sup>11</sup> It is the largest programme to date in England run by three charities (Mental Health Media, MIND, and Rethink) with £18 million in funding (<http://www.time-to-change.org.uk/>).

<sup>12</sup> National daily - Daily Express, Daily Mail, Daily Mirror, Daily Star, Daily Telegraph, Guardian,

were sampled on two randomly chosen days of every month using thirty-five terms like "mental illness" or "schizo" or "psychotic". Each article found was coded for stigmatising or anti-stigmatising themes, or mixed or neutral <sup>13</sup>. There were 3001 articles in total <sup>14</sup>.

Over the four years of the study period, there was a significant increase in anti-stigmatising themes from 31% of articles in 2008 to 41% in 2011. But there was no change in the amount of stigmatising themes (46% of articles in 2008 and 45% in 2011) (figure 3).



(Data from Thornicroft et al 2013 table 1 pS66)

Figure 3 - Coding of articles (%).

Individuals with mental illness, their families, friends or carers, and mental health charities were quoted more often in articles in 2011 than in 2008 (figure 4).

Thornicroft et al (2013) observed:

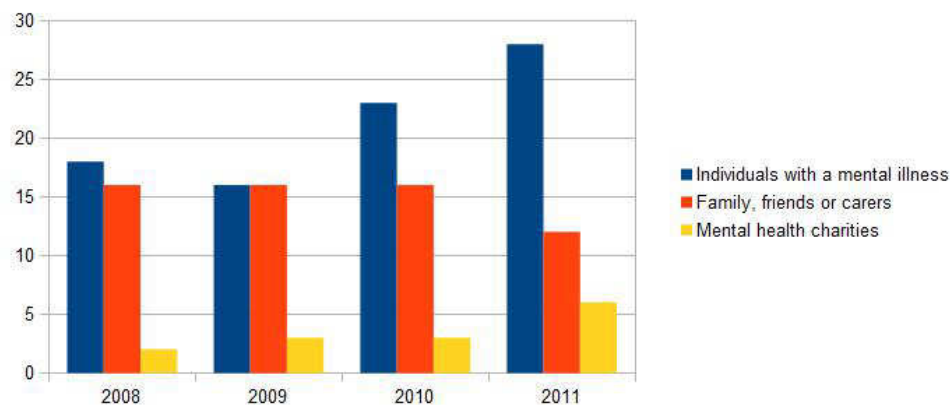
We were unable to determine whether the increase in anti-stigmatising articles was due to an increased awareness among reporters of the impact of their content and style regarding the portrayal of mental

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Independent, Sun, and The Times. National Sunday - News of the World, The People, Sunday Express, Sunday Mail, Sunday Mirror, Sunday Star, Sunday Telegraph, Sunday Times, and The Observer. Local newspapers - Birmingham Evening Mail, Eastern Daily Express, Evening Chronicle, Evening Standard, Hull Daily Mail, Leicester Mercury, Liverpool Echo, Manchester Evening News, and The Sentinel.

<sup>13</sup> Stigmatising themes - danger to others, problem for others, hopeless victim, strange behaviour, personal responsibility causes, sceptical of seriousness, or pejorative or inappropriate language. Anti-stigmatising themes - sympathetic portrayal, causes of mental illness (genetic, psychosocial or other), recovery from or successful treatment of mental illness, or mental health promotion.

<sup>14</sup> Articles - 882 (2008), 794 (2009), 627 (2010), and 698 (2011).



(Data from Thornicroft et al 2013 table 3 pS67)

Figure 4 - Percentage of articles quoting sources.

health issues as a result of the TTC programme, or whether - since the proportion of stigmatising articles did not change significantly across the same period - the increase in anti- stigmatising articles reflects an awareness among journalists of public demand for articles that portray mental health issues in a non-stigmatising manner. The latter is more likely, as in order to change the tone and content of articles relating to mental illness across all print media in England, intensive work with reporters and editors would be required (pS68) <sup>15</sup>.

The study had the following limitations (Thornicroft et al 2013):

- Placing articles in simple categories (eg: stigmatising) loses the complex meaning.
- The accompanying photographs and headlines of the article were not coded, only the text.
- A different researcher coded the articles for each year (inter-rater reliability of over 80% between them).
- The study did not include magazines.

<sup>15</sup> They also said: "A notable finding from this study is that more of the articles featuring 'mental health promotion' were reported in local rather than in national newspapers... This type of 'grass roots' mental health promotion material, covering for example local fund-raising activities, might be an effect of the TTC campaign, in that more recently people are less ashamed to raise awareness about mental illness, possibly indicating a reduction in the levels of stigma attached to this type of illness" (Thornicroft et al 2013 pS68).

Evans-Lacko et al (2013) evaluated the success of TTC in changing public attitudes and behaviour towards individuals with mental illness. They analysed data collected nationally each year from 1700 respondents in the "Attitudes to Mental Illness" survey. The survey covered knowledge about mental health and mental illness<sup>16</sup>, attitudes<sup>17</sup>, and reported and intended behaviour (eg: actually working with such individuals or willingness to).

Between 2009 and 2012, the overall knowledge score, and reported behaviour did not change, but attitudes has a positive change as did intended behaviour.

## **5. APPENDIX A - DEFINING AND CLASSIFYING MENTAL ILLNESS**

MacSuibhne (2009) noted that "Defining what psychiatry is and what mental illnesses are can often seem a circular process"<sup>18</sup>.

The medical model is the dominant view in psychiatry today. "People present with symptoms and exhibit signs which are examined. If these symptoms and signs are deemed to provide evidence of pathology, they lead to a diagnosis of an illness. Investigations and treatments are ordered. Medications and other interventions are prescribed to treat the illness. The cessation of the symptoms and signs marks recovery from the illness. This is, on the surface, similar to how an ophthalmologist would approach cataract, or a respiratory physician chronic obstructive pulmonary disease" (MacSuibhne 2009 p214).

The accuracy of diagnosis of mental illness depends on the validity of the classification system used (ie: "a diagnosis of schizophrenia is in fact a case of schizophrenia") and its reliability (eg: "other clinicians would come up with a diagnosis of schizophrenia given the same case") (MacSuibhne 2009)<sup>19</sup>.

"Psychiatrists spend much of their time trying to improve the image of psychiatry within medicine by insisting it is a scientific enterprise, characterised by the assumptions of expertise, specialist knowledge and greater objectivity that (it is assumed) are possessed in

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<sup>16</sup> Eg: "People with severe mental health problems can fully recover" (true) and "Most people with mental health problems want to have paid employment" (true).

<sup>17</sup> Eg: "I would not want to live next door to someone who has been mentally ill", "People with mental illness are a burden on society", and "People with mental illness don't deserve our sympathy".

<sup>18</sup> For example, "Mental illness is treated by psychiatrists, and who are psychiatrists? They treat mental illness. This allows the language of psychiatry to be adopted as a form of rhetoric" (MacSuibhne 2009 p223).

<sup>19</sup> One service user admitted to Beresford (2002), "if we are seen to question the idea of 'mental illness', then that may just be taken as further evidence of our irrationality, leading us to being further discredited and excluded" (p582).

full by other medical specialties" (MacSuibhne 2009). Part of the reason is that the concept of "mental illness" or "abnormality" is contested by other approaches than the medical model, including a behavioural/psychological model that sees abnormalities as learned behaviours, psychoanalytic models with the focus upon the unconscious mind, and critical/sociological models that class mental illness as labelling and social control.

Thomas Szasz (eg: 1960) has been most critical of "mental illness", arguing that, in fact, it is a "problem with living". "Szasz has never stated that the phenomena described as mental illnesses do not exist – that people who are diagnosed with depression are not suffering from distress, or that people who are diagnosed with paranoid schizophrenia are not reporting persecution without a basis in real events. Szasz simply states that these presentations are not illnesses, and their treatment as such is not simply an intellectual error but has lead to massive violations of human rights on a worldwide scale" (MacSuibhne 2009).

A distinction is often made between "disease" ("a value-free objective reality") and "illness" ("a value-laden, socially determined process or consequence of disease") (MacSuibhne 2009). Many critics of psychiatry view physical illness as the former and mental illness as the latter.

But Kendell (1975), for example, argued for a "value-free" concept of illness using the idea of "biological disadvantage" (ie: abnormal processes in a living organism that place the organism at biological disadvantage to the norm for the species) (MacSuibhne 2009) <sup>20</sup>.

Canguilhem (1989) took the position that "a purely 'scientific', lab-based understanding of illness divorced from clinical experience or understanding the conditions of disease is impossible – 'it is first and foremost because men feel sick that a medicine exists. It is only secondarily that men know, because medicine exists, in what way they are sick' (Canguilhem 1989 p229)" (MacSuibhne 2009 p219). Fulford (eg: 1993) preferred to see disease as a "failure of function" (eg: the kidneys fail to remove impurities from the body), and illness as "failure of action" (eg: an individual is unable to do they want or should do).

Key to understanding psychiatry and the "truth" of mental illness is the classification systems for particular mental disorders. But Grob (1991) observed

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<sup>20</sup> Kendell (2002) accepted that value judgments were inescapable in relation to illness (MacSuibhne 2009).

that "classification systems are neither inherently self-evident nor given. On the contrary, they emerge from the crucible of human experience... Indeed, the ways in which data are organised at various times reflect specific historical circumstances" (p421).

Grob (1991) listed factors that have influenced the development of such classification systems, including:

- Ideology/beliefs of psychiatrists.
- Their desire for status and legitimacy.
- The characteristics of patients.
- Broader social contexts.

The first edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-I) appeared in 1952 in the USA (table 7). The process of arriving at that point can show the above factors at work (ie: the history of DSM). For example, in the nineteenth century, illness (whether mental or physical) was due to an imbalance between nature, society and the individual. "Thus, insanity often followed violation of the natural laws that governed human behaviour and was linked as well with immorality, improper living conditions, or other stresses that upset the natural balance" (Grob 1991 p422). Classification systems were of limited importance at this time.

VERSION	YEAR	TOTAL NUMBER OF DISORDERS (NUMBER OF PAGES)
I	1952	106 (130)
II	1968	182 (134)
III	1980	265 (494)
III-R	1987	292 (567)
IV	1994	297 (886)

(Source: Mayes and Horwitz 2005)

Table 7 - DSMs I-IV.

The ideas of Emil Kraepelin in the 1890s began an interest in classification as he identified specific patterns and diseases (eg: dementia praecox). In the USA, the collection of statistics by the Bureau of the Census also played a role. This led to the "Statistical Manual for the Use of Institutions for the Insane" in 1918 with twenty-two principle groups of mental disorders (Grob 1991). The tenth edition of this appeared in 1942.

World War II was the next important event in the history of DSM as the psychological consequences of

combat were seen. "In the post-war era, the traditional preoccupation with the severely mentally ill in public mental hospitals slowly gave way to a concern with the psychological problems of a far larger and more diverse population as well as social problems generally. Persuaded that there was a continuum from mental health to mental illness, psychiatrists increasingly shifted their activities away from the psychoses toward the other end of the spectrum in the hope that early treatment of functional but troubled individuals would ultimately diminish the incidence of the more serious mental illnesses" (Grob 1991 p427).

DSM-I was published in 1952 by the American Psychiatric Association (APA). It divided mental disorders into those impairments of brain function (eg: Huntington's chorea) and an inability to function generally (eg: manic-depressive). The underlying assumption of DSM-I was psychodynamic rather than the bio-medical model (which underlies later editions) (Grob 1991).

DSM-III, which appeared in 1980, was the next key step in the history of DSM as the psychodynamic origins of psychiatry were removed. A new model that "equated visible and measurable symptoms with the presence of diseases" with a more standardised system of measurement (Mayes and Horwitz 2005). This "allowed research-oriented psychiatrists, a small but highly influential group in the profession, to measure mental illness in reliable and reproducible ways. It also helped silence the critics of the previous system, who claimed that mental illnesses could not be defined in any objective way. For clinicians, who comprised the vast majority of the psychiatric profession, the new diagnostic system legitimised claims to be treating real diseases and, most importantly, allow them to obtain reimbursement from third-party insurers" (Mayes and Horwitz 2005 pp251-252).

DSM-II had been faced with a number of critical voices in the 1970s "which damaged psychiatry's status as a genuine medical specialty" (Mayes and Horwitz 2005) including:

- The "anti-psychiatry" movement.
- Health insurance companies in the USA who refused to pay out for mental health claims because of a lack of clarity in diagnosis.
- The growth of drug treatment (with or without success) rather than therapy.
- Psychiatrists wanting their discipline to have a more "scientific" basis. "Medical training seemed irrelevant for the understanding of the central dynamic processes of repression, childhood sexuality, and symbolic interpretation of symptoms" (Mayes and Horwitz 2005).

"With the DSM-III, biomedical investigators replaced

clinicians as the most influential voices in the field... Consequently, psychotherapy became the primary domain of clinical psychologists, counsellors, and social workers, who appeared to practice it as effectively as psychiatrists but who charged less. Psychopharmacological therapy became the private 'turf' of medically trained psychiatrists" (Mayes and Horwitz 2005 p265).

The developments of subsequent DSMs can be seen as "an upward gradient toward an ideal end" where "the final goal is a definitive and presumably unchanging nosology of mental illness". On the other hand, "more sceptically minded historians" (and others) may see that the "only constant is the process of change itself" with a "perennial human yearning for omniscience" (Grob 1991) <sup>21</sup>. It also shows the social constructed nature of mental illness (table 8).

Owen (2008) described the "hubris syndrome" among certain heads of government. He named four - David Lloyd George, Margaret Thatcher, George W Bush, and Tony Blair.

There are thirteen symptoms (with 3 or 4 needed for a diagnosis) including:

- a narcissistic propensity to see the world primarily as an arena in which they can exercise power and seek glory rather than as a place with problems that need approaching in a pragmatic and non-self-referential manner.
- a predisposition to take actions which seem likely to cast them in a good light, taken in part in order to enhance their image.
- a disproportionate concern with image and presentation.
- a messianic manner of talking about what they are doing and a tendency to exaltation in speech and manner (Owen 2008 p428 quoted in MacSuibhne 2009 p213).

MacSuibhne (2009) questioned whether hubris syndrome could be classed as a mental disorder - "what Owen is described is not pathological for individual but for wider society" (p223).

Table 8 - An example of a "new mental disorder".

Relman and Angell (2002) lamented the power of the pharmaceutical industry in the USA: "It uses its great wealth and influence to ensure favourable government policies. It has also, with the acquiescence of a medical

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<sup>21</sup> Mayes and Horwitz (2005) observed that "DSM-III's creation was not the result of a carefully orchestrated conspiracy, but neither was it an accident or 'chance-like sequence' of events as some have argued. It did not stem from any new knowledge about the causes of mental illnesses nor their treatments. In addition, it did not enlarge the realm of behaviours that the psychiatric profession was to treat. Instead, its symptom-based focus stemmed from the efforts of research-oriented psychiatrists who wanted to standardize diagnostic criteria and focus attention on the symptoms of mental disorders, rather than on their underlying causes" (p265).

profession addicted to drug company largesse, assumed a role in directing medical treatment, clinical research, and physician education that is totally inappropriate for a profit-driven industry... The drug companies pay the piper, and by one means or another they call the tune; and the tune is keyed to their sales pitch" (pp27 and 34).

"The pharmaceutical industry justifies its extraordinary profits largely by the claim that they are necessary as an incentive to continue its vital research. The implication is that if the public wants new cures for diseases, it should give the industry free rein. It is important, then, to ask just how innovative the pharmaceutical industry really is" (Relman and Angell 2002 p30). The answer is that many new drugs are "me-too drugs" (where drugs prescribed for one condition are licensed for use with another condition) (Relman and Angell 2002).

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## **2. DIFFERENT QUESTIONS GET DIFFERENT ANSWERS ON OPIOID MISUSE**

How many individuals take drugs for recreational reasons? Shield et al (2013) showed that the answer to this question depends on how a questionnaire is designed. This measurement effect was found in surveys of non-medical prescription opioid use (NMPOU) (ie: painkillers) in Canada. This is using prescription opioid analgesics (POAs) when not prescribed by a doctor or using them for purposes other than prescribed.

The Canadian Alcohol and Other Drug Use Monitoring Survey (CADUMS) investigated NMPOU in 2008 in adults in the general population over fifteen years of age with the following questions:

1. During the past 12 months, did you ever use pain relievers for the feelings [they] caused or to get high?", and/or
2. Were the pain relievers used during the past 12 months obtained from (i) a prescription written for someone else such as a family member or a friend, (ii) bought from someone else, without a prescription, (iii) from any other source (Shield et al 2013).

A prevalence rate of 0.4% was found (Health Canada 2009).

But in the USA in 2008 among the general population (12 years old and above), a rate of 4.8% was reported by the National Survey on Drug Use and Health (NSDUH) (SAMHSA 2009). This used the question: "Have you ever, even once, used [name of prescription opioid] that was not prescribed for you or that you took only for the experience or feeling it caused?" (Shield et al 2013) to measure NMPOU. Shield et al (2013) felt that the NMPOU rate in Canada should be closer to the US figure because of the roughly equal number of POAs.

Shield et al (2013) used the Centre for Addiction and Mental Health (CAMH) Monitor Surveys in 2008, 2009 and 2010 in Ontario, Canada to compare different questions about NMPOU. Adults aged eighteen years and above were sampled by random-digit telephone dialling. In 2008 and 2009, respondents were asked:

1. Thinking about all the pain relievers you have used during the past 12 months did you get any of them (i) from a prescription written for someone else such as a family member or a friend, (ii) bought from someone else, without a prescription and/or (iii) from any other source (defined as a source other than the previously mentioned sources and a prescription written for you), and
2. During the past 12 months, did you ever use pain relievers for the feelings it caused or to get high? (Shield et al 2013).

While in 2010, one question was asked: "In the past 12 months how many times, if at all, have you used any such pain relievers without a prescription or without a doctor telling you to take them?". In all cases, POAs

were defined as "pain relievers that are obtained by a prescription from a doctor or dentist such as Percocet, Percodan, Demerol, OxyContin, Tylenol #3 or other products or pain relievers with codeine that are obtained in a pharmacy. Some people use these medications to treat pain resulting from an illness, injury" (Shield et al 2013).

The prevalence rate of NMPOU in 2008 and 2009 was 2.0% <sup>22</sup>, but 7.7% in 2010 <sup>23</sup>. This was a significant difference ( $p < 0.001$ ).

Shield et al (2013) noted: "It is highly unlikely that the extensive NMPOU prevalence differences observed from the different survey items reflect an actual increase of NMPOU or changes in NMPOU determinants, but rather point to measurement effects. It appears that we currently do not have accurate estimates of NMPOU in the Canadian general population, even though these estimates are needed to guide and implement targeted interventions". For example, in the USA, for the same period (2008-2010), prevalence rates remained around 4.8%.

There are methodological limitations that could have accounted for small differences only:

- Only telephone survey, which excludes individuals without a telephone, who are more likely than the general population to use drugs (Bruneau et al 2012).
- Only English and French speakers.
- Respondents to telephone surveys are less likely to engage in health-harming behaviours (Shield and Rehm 2012).

Generally, self-reported questionnaires are subjective measures in cases like this, and differences in responses depends on comprehension of the questions asked, recall of information, and honesty (Shield et al 2013).

Differences between studies, like corrections (table A) in academic literature, can be viewed as weakness in the popular media that wants absolute facts and truths, or even sees changes as a sign of fraudulent research. But "because human knowledge is by definition fallible, correction remains a necessity" (Grcar 2013). In fact, Kuhn (1970) saw corrections and revisions as part of

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<sup>22</sup> 2.3% in 2008 and 1.7% in 2009.

<sup>23</sup> In terms of gender differences, men 2.4% and 8.1%, and women 1.6% and 7.4% respectively.

paradigm shifts (ie: progress).

For example, the average rate of correction of published articles in psychology is below 3% over the last twenty years (when up to 0.5 million articles are published each year) (Grcar 2013).

- Addendum - clarify or expand previous article.
- Erratum - correct publication error.
- Retraction - withdrawn for gross errors in methodology, say, or deliberate misconduct.
- Update - revision of entire article.

(Source: Grcar 2013)

Table A - 4 types of correction in academic articles.

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