Declaring Label Preferences: Terminology Research in Mental Health

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ABSTRACT

This exploratory descriptive research attempts to determine current preferences and understandings of terms used to refer to persons with a mental illness. From September 2005 to January 2006, 760 surveys were completed across Canada at mental health conferences and meetings, via provincial and national mental health websites, and during college classes. Respondents were asked to indicate whether they were a mental health service provider, an individual with mental illness, a friend or family member, or someone not in the three categories mentioned. Quantitative and qualitative data were collected. Analyses of the data indicate that respondents show an aversion to labels, and a majority of respondents prefer to use the term *individual* or the person's name.

Keywords: labels, stigma, preferences, mental health, terminology

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Labels used to address people with mental illness are a prominent concern in the mental health field. Throughout the recorded history of mental illness, specific language and labels have been developed to describe behaviour. People who behaved differently were feared and labelled with derogatory terms. In the past, terms such as *lunatic, loony, psycho, schizo, maniac*, and others were often chosen on the basis of scientific or pseudo-scientific theories that are now grossly outdated. For instance, *lunatic* was originally intended to capture changes in human behaviour based upon lunar cycles (Mish, 1984). However, studies completed by Durm, Terry, and Hammonds (1986) and Little, Bowers, and Little (1987) failed to demonstrate any connection between the lunar phases and abnormal behaviour in people with mental illness. *Schizo* is the title of a drama or horror movie released in 1978, whose tagline was "when the left hand doesn't know who the right hand is killing" (Walker & McGillivray, 1976, para. 2). These terms are now understood as both stigmatizing and inaccurate labels that tend to isolate people from the rest of society. Unfortunately, service providers, family and friends, and the general public are still using some of these terms.

Labelling implies a separation of "us" from "them." This separation easily leads to the belief that "they" are fundamentally different from "us"; over time, "they" come to believe that "they *are* the thing being labeled" (Link & Phelan, 2001, p. 370). The separation can be twofold: The individual with mental illness often withdraws due to the felt stigma, and some members of the general public may perceive people with mental illnesses as dangerous and choose to maintain a greater social distance (Penn, Guynan, & Daily, 1994). Language can therefore be a powerful source and sign of stigmatization (Link & Phelan, 2001).

Labels affect not only how individuals see other people, but how they see themselves. Concerns over terminological choices and the possibility of an accompanied stigma are a significant issue in the mental health field. The terms used to refer to persons with mental illness can influence the perceptions of service providers, individuals receiving services, and the general public as a whole (Wahl, 1999).

Furthermore, members of a group may disagree about what terminology is acceptable and what is not. Terms that originally seemed inoffensive can develop negative connotations over time, become dated, or go out of style as awareness changes. Therefore, what terms are acceptable shift constantly as people become more aware of language, its implications and power.

This exploratory descriptive study was conducted using a survey-based research design. No hypotheses were proposed or tested. The surveys were employed to determine current preferences and understandings of terms used when referring to persons with mental illness. The research also sought to determine if certain terms are preferred or avoided, and by whom.

THEORETICAL BACKGROUND

A theoretical approach underlies this and other studies that are concerned with how individuals are addressed or categorized. Terms can serve more than a simple denotative function. Some terms carry descriptive content that specifies such things as the relationship between the person referred to and his or her community. For instance, the term *patient* describes the relationship between individuals and their physicians. This theoretical stance connoted by language can vary in intensity and degree but shares the central thesis that our social reality is some way constructed (Berger & Luckmann, 1966). Michael Walker (2006) acknowledged that from the linguistic paradigm and postmodern perspective, language creates realities as opposed to discovering them. He argued that *mental illness* diagnoses and associated concepts are really social constructions. Language can intentionally or unintentionally cause offense or perpetuate discriminatory values by emphasizing differences between people or groups. Words are extremely powerful to implement change but just as powerful to strengthen and maintain a situation.

Following this line, when examining terms used to describe mental illness today, one wonders if these terms emphasize distinctiveness of a community or specify a particular relationship. It appears that the concept of abnormality and mental illness changes with the available knowledge and the prevailing social attitudes. Barber (2007) and Bell (2007) described how individuals labelled *mentally ill* address and resolve the dissonance between the social construction of their illness and their personal construction of its meaning by affirming their identities as people. They see themselves as people with an illness, rather than as mentally ill people. There is a considerable difference between self-defined and culturally defined label identities and values.

The social construction of mental illness can be internalized; the person then expresses the construction by means of symptoms, which are interpreted by another social construction of terms, thereby having a profound effect on the symptomatic experience the person has (Young, 2009). The collective symptoms describing mental illness have been in a constant state of negotiation among opinion makers, stakeholders, and interest groups who try to "shape the evolution of psychiatric diagnoses" (Dowbiggin, 2009, p. 436) according to the social thinking of the day.

Burr and Butt (2000) stated that it is possible for postmodern psychology to assist people with mental illness in constructing new vocabularies—new worlds of meaning and relationships. Therefore, with the help of evidence-based research and increased awareness, and by verbal example, changes in the use of labels can be achieved.

Labelling, Stigma, and Mental Illness

Acquiring the label *mentally ill* is a life-altering event for many individuals and one that may have long-lasting repercussions. Hayne (2003) suggested that the "diagnostic label becomes a transforming influence" (p. 722), and may actually shape one's expectations for present and future experiences. He described a diagnosis of mental illness as having the power to "devastate the identity of individuals designated ill and impose lifelong limitations through prophetic labeling" (p. 722). This labelling effect may be particularly influential for those with severe and persistent mental illness, such as schizophrenia, which is well known but often misunderstood by society. As Roe, Chopra, Wagner, Katz, and Rudnick (2004) stated, unlike "having other chronic or debilitating illnesses, having schizophrenia may entail becoming a 'schizophrenic' which involves a transformation of self, as known subjectively by the individual, and of identity, as known objectively by others" (p. 353). In this way, the label itself can influence the public's opinion of the individual as well as his or her own sense of self.

The negative effects of labelling people with mental illness have found support in a study conducted by Sari, Arkar, and Alkin (2005). They found that "a mental illness label, regardless of a person's behavior, can result in negative attitudes" (p. 28) and an increased desire for social distance from the individual. Thus the

label itself, rather than disruptive or socially unacceptable behaviours, may create negative feelings among the general public and a desire for separation from people with mental illnesses. Similarly, Angermeyer and Matschinger (2003) found that among those who perceive people with mental illness to be dangerous, labelling fosters high social distance.

Theoretical support for the negative effects of labelling was also provided by Link, Cullen, Struening, Shrout, and Dohrenwend (1989). Working from Scheff's (1966) original labelling theory, Link et al. proposed and found support for their modified labelling theory. This theory contends that labelling can lead to negative outcomes, such as decreased social supports, secrecy, and withdrawal. According to the modified labelling perspective, individuals are socialized by their culture to hold a particular set of beliefs regarding how most people treat those with mental illness. Once a person enters treatment for a mental illness, these beliefs take on a new meaning, not only for societal perceptions but for the beliefs of individuals themselves. Link et al. stated that "the more patients believe that they will be devalued and discriminated against, the more they feel threatened by interacting with others which can lead to negative consequences for social support networks, jobs, and self-esteem" (p. 440). The authors also suggested that these negative outcomes might increase the patient's social and psychopathology risk factors for the development of prolonged or recurrent psychopathology. This theory posits that acquiring the label of a mental illness and one's beliefs about the implications of that label can have extensive negative consequences for the individual. For language and labels have a power of their own—a power that can result in stigma and discrimination.

The stigma of being labelled as mentally ill is a significant barrier not only in western society but also around the world (Rusch, Angermeyer, & Corrigan, 2005). In a report released by the United States Department of Health and Human Services in 1999, stigma was declared "the most formidable obstacle to future progress in the area of mental illness and health" (Hinshaw & Cicchetti, 2000, p. 556). In addition, Corrigan and Penn (1999) stated that "stigma's impact on a person's life may be as harmful as the direct effects of the disease" (p. 765). Stigma associated with a mental illness cuts across all ages, classes, and social groups and may be expressed in a myriad of life's arenas, including social, legal, economic, personal, and familial situations. As such, it is vitally important to consider the role that stigmatization plays in the life experience of an individual with a mental illness.

Dohrenwend and Dohrenwend (1981) described one of the most devastating effects of labelling and the consequent stigma as early as 1981. They believed that, for some people, labelling and stigma might increase the vulnerability and likelihood of experiencing repeated episodes and extension of the mental illness.

The language of labelling and consequent stigma has been grappled with for years and no consensus has been reached. Is it possible that the captivating, frustrating, and never-ending discussion is indeed the solution? "Diverse speculation is a wonderful antidote to the falsehood of certainty" (Oaks, 2009, para. 30).

Related Research

A number of articles have been written about the word choice between patient and client in the health care field. Seven studies specific to labelling were found in this area. Three were conducted in physical care settings and four in mental health settings. Elliot and White (1990) surveyed 343 visitors to a hospital open-day event in New Zealand and found that 87% preferred to be called patient. The authors found

little difference in the responses between males and females, but preference for patient increased with age. Wing (1997) found similar results in his survey of 101 people who were registered at a back pain clinic at Vancouver Hospital in British Columbia, Canada. To investigate the belief among some health care providers that traditional terminology conveys negative attitudes, Wing asked if it empowers consumers in health care to become stakeholders if they are called clients rather than patients. Seventy-four people receiving care preferred patient. Wing concluded that patient remains the best single term for an individual receiving health care. He also stated that social training has taught him that it is common courtesy to inquire of a person what he or she wishes to be called.

Deber, Kraetschmer, Urowitz, and Sharpe (2005) surveyed 606 people in Ontario, Canada: 202 had breast cancer, 202 had prostate disease, and 202 were from a fracture clinic. The survey asked these people to choose which label they preferred between patient, client, customer, consumer, partner, and survivor. A 5-point Likert scale was used with responses ranging from *strongly like* to *strongly dislike*. The first choice of all individuals with a physical illness was patient with a range of 79–82%. The second choice was survivor with 21%, but mostly among individuals who had breast cancer, which is in keeping with terminology used in cancer treatment. The other alternatives evoked moderate to strong dislike.

To determine how persons receiving mental health services would like to be addressed, Mueser, Glynn, Corrigan, and Baber (1996) surveyed 302 people from a variety of inpatient and outpatient psychiatric programs in the United States. Forty-five percent of these individuals preferred the term client, 20% preferred patient, 8% preferred consumer, and 27% expressed no clear preference. Sharma, Whitney, Kazarian, and Manchanda (2000) conducted a similar study at four psychiatric settings in Ontario, Canada, using the same three label choices plus survivor. They surveyed 550 service providers and 427 recipients of services and found that 68.4% of service providers preferred the term patient, but that among recipients there was no universal preference for terminology.

Lloyd, King, Bassett, Sandlord, and Savige (2001) conducted a study in an Australian regional mental hospital. One hundred and twenty-five individuals who were participating in a number of inpatient and outpatient programs were asked to indicate a preference between the terms patient, client, or consumer. The findings indicated that 34% preferred client, 28% preferred consumer, 23% preferred patient, and the rest had no preference. The analysis suggested that the term preferred depended on the treatment setting and that gender or age had little effect on the word chosen.

In a recent large (n = 1,827) multi-site study in the United States, Covell, McCorkle, Weissman, Summerfelt, and Essock (2007) examined the respondents' preferred term to describe their status as recipients of mental health services. The researchers applied logistic regression to examine whether preference varied by gender, race, or diagnosis. Preferred terms were client 39%, patient 22%, consumer 16%, and survivor 11%. Controlling for site, preferences did not vary by gender, race, or diagnosis. They concluded that this lack of consensus suggests researchers, clinicians, administrators, and policy-makers should be sensitive to preferences expressed by individuals receiving care.

To summarize, the findings of the known available research from Australia, Canada, New Zealand, and the United States indicated the following preferences. The preferred term in physical care settings was patient. In mental health settings the preferred terms were divided between patient and client, except for the

Australian study where 28% of individuals chose consumer. The results could have been influenced by the fact that two of the studies offered only patient, client, and consumer while the other two added survivor to the choices.

It may be concluded that terminology currently used in the mental health field may not accurately reflect terms that service recipients, providers, and others consider acceptable. Furthermore, there may not be a consensus on what terms are acceptable. Terms such as consumer and survivor, for example, are applied to people with mental illness despite what may be inappropriate connotations. The media constantly refer to consumers as purchasers of products, and the term survivor is used by the Cancer Society to designate people who have lived specific lengths of time since a diagnosis was made (Twombly, 2004). This study was undertaken out of concern that these and possibly other terms could be seen as inappropriate, stigmatizing, and degrading when applied to people with mental illness. To date there is little research in this area.

This research study made no attempt to replicate the above studies due to a desire to increase the breadth of choices of labels and the numbers of categories of respondents. As opposed to the other studies whose respondents were primarily facility based, the people who responded to this survey were totally community and online based. In fact, the majority of studies concerning labelling have relied primarily on mental hospital data (Thoits, 2005). In contrast, this study focused on a community mental health context to determine preferences between 10 presented terms: consumer, client, participant, patient, subject, stakeholder, patron, person with a ... (specific illness), mentally ill, and individual. We did not undertake the task of determining the appropriate terms to refer to groups of individuals and consciously addressed preferences only as they pertained to referencing individuals. It is believed that the findings of this research are useful particularly to service providers as they interact with people who have mental illness, and service recipients as they work to cope with their illness.

This research study was designed to meet the following three objectives: (a) determine labelling preference patterns among individuals who completed the survey; (b) document attitudes toward certain terms presently used to refer to persons with mental illness; and (c) determine when and why certain terms are preferred or avoided. The rationale for this study also included a desire to raise awareness about current labelling and to promote discussion about terminology in the mental health field.

METHODS

We developed a six-section, structured questionnaire using closed and open-ended questions to collect both quantitative and qualitative data. Participants were asked to choose from 10 different terms that could be used to refer to a person receiving mental health services. Surveys were collected from September 2005 to the end of January 2006.

Population, Sample, and Setting

Participation in the study was voluntary and represented individuals who attended the Canadian Mental Health Association (CMHA) National Conference in Edmonton, Alberta, and the Annual General Meeting and various educational sessions of the Canadian Mental Health Association, Central Alberta Region. In order to expand the breadth and possibly the ages of the respondents, we invited several classes of students at Red

Deer College to complete the survey. The survey was also posted on the national and provincial websites of the Canadian Mental Health Association from November 1, 2005, until January 31, 2006. A total of 760 surveys were completed, 427 manually and 333 online.

According to self-identifying categories requested in the survey, 295 people identified themselves as mental health service providers, 215 stated they were persons experiencing or who had experienced mental illness, and 314 people said they were a friend or family member of a person experiencing or who had experienced mental illness. Two hundred and thirty-three people identified themselves in the *other* category without indicating a specific designation.

Instrumentation

To develop the survey, we first conducted a literature search to determine what terms are being used to address people experiencing mental illness. The choice of terms was also influenced by anecdotal evidence taken from active members in the mental health community including clients, support workers, and staff of the Alberta Central Region office of the Canadian Mental Health Association. The survey was pretested locally using a convenience sample of individuals with mental illness, health workers, and board members. The wording was then reworked to ensure clarity and user friendliness.

The survey consisted of six sections.

- Section I asked respondents to rate their preferences of 10 terms using a 5-point Likert scale ranging from *strongly disagree* to *strongly agree*.
- Section II asked respondents to choose or suggest phrases to describe the following labels: consumer, client, participant, stakeholder, and patron.
- Section III asked respondents which of the 10 labels they would use when speaking to a co-worker, family or friend, or person with a mental illness.
- Section IV asked respondents to identify their role as (a) health care provider, (b) person experiencing or who had experienced a mental illness, (c) family or friend, and (d) other.
- Section V invited respondents to suggest other terms that they preferred when speaking of someone with a mental illness.
- Section VI elicited further comments and concerns about mental health terminology.

Ethical Considerations

The survey cover sheet explained that the surveys would be completed in a voluntary, confidential manner, and that personal anonymity was guaranteed. No identification of individuals could be matched to a completed survey. The cover letter also stated that the study findings might be presented at academic conferences or submitted for publication in an academic journal. The survey met Alberta's Freedom of Information and Protection of Privacy Act guidelines and received Certification of Ethical Acceptability for Research Involving Human Subjects from the Human Research Ethics Committee of Red Deer College, Red Deer, Alberta. In order to eliminate all identifying data from the online surveys, they were submitted

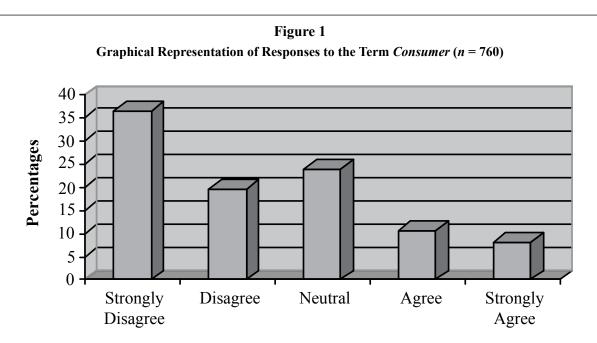
to the webmaster@cmha.ca site and then sent electronically to a research committee member at the CMHA Alberta Central Region office.

ANALYSES OF THE DATA

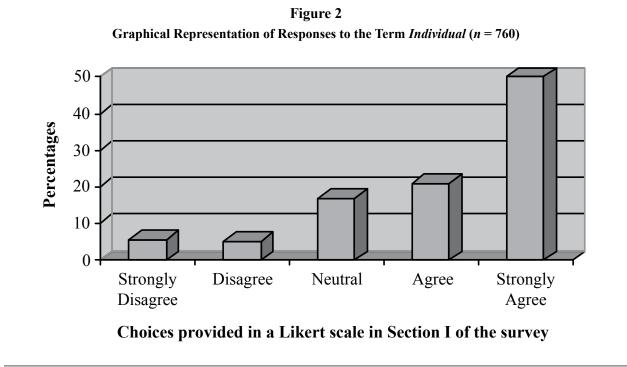
Quantitative Data

A total of 760 surveys were analyzed with respect to the quantitative and qualitative data. The Statistical Package for Social Sciences (SPSS) program, version 13, was used to complete the statistical analysis. Frequencies, percentages, cumulative percentages, and valid percentages were determined. A Pearson chisquare analysis was conducted on 527 surveys. Although the survey asked individuals to choose the identity that *best* described them, 233 people chose more than one identity. Therefore, the total sample of 760 was reduced to 527 by eliminating any surveys where respondents identified themselves in more than one category.

In Section I, most respondents either *strongly disagreed* or *disagreed* with the terms consumer (56.3%), participant (48.3%), patient (48.7%), subject (85.9%), stakeholder (70.2%), patron (68.5%), and mentally ill (67.5%). Respondents mostly *agreed* or *strongly agreed* with the terms client (47.3%), person with a ... specific illness (51.1%), and individual (71.1%). The bar graphs in Figures 1 and 2 illustrate responses to the terms consumer and individual.



Choices provided in a Likert scale in Section I of the survey



In Section II of the survey, respondents were asked to choose or suggest phrases to describe what five of the labels meant to them. The labels consumer, client, participant, stakeholder, and patron were chosen because these terms were more likely to have different meanings for different people. For the term consumer, 82.2% of all respondents stated that they thought of someone purchasing a product or service but *not* having a physical/mental illness, requiring a service, or making a choice. For client, 84.9% of respondents thought about someone obtaining a service. For participant, 96.4% thought about someone who partakes in an activity or is part of a group. For stakeholder, 78.4% thought about someone who has something to lose if a service is discontinued. For patron, 73.4% thought about someone who supports a particular cause.

Section III of the survey asked respondents to select all terms that applied when speaking about someone with mental illness to co-workers, family or friends, and when addressing individuals themselves. When speaking to co-workers, 62.4% of all respondents preferred to use person with a ... (specific illness), 58.7% preferred individual, 47.1% preferred client, 33.9% preferred patient, and 40.1% preferred mentally ill. Only 22.6% indicated they would use consumer, and very low percentages would use participant (13.8%), stakeholder (5.4%), subject (4.2%), or patron (1.2%).

When speaking to "my family or friends," 67.4% of all respondents preferred to use person with a ... (specific illness), 54.4% preferred individual, 47.6% preferred mentally ill, 37.9% preferred client, and 30.4% preferred patient. Very low percentages indicated consumer (14.3%), participant (9.5%), stakeholder (3.0%), subject (2.5%), and patron (0.7%).

When speaking to a person with a mental illness, the highest percentage—67.8% of all respondents preferred to use the term individual. Other preferences were person with a ... specific illness (44.5%), client (30.1%), patient (24.3%), mentally ill (24.1%), consumer (15.0%), participant (12.6%), stakeholder (3.9%), subject (2.0%), and patron (0.9%).

A Pearson chi-square analysis of the 527 responses was conducted to determine whether preferences differed among groups of respondents; in other words, was there was a significant association between the self-identification category (Section IV) and the language used to refer to someone with a mental illness (Section I)? Of the 527 respondents there were 166 mental health service providers, 67 individuals experiencing a mental illness, 127 family and friends, and 167 who responded in the role category labelled *other*.

For each of the 10 items, a Pearson chi-square analysis was performed. A significant chi-square finding means that there is a tendency for one or more groups to like or dislike a term more than other groups do. A nonsignificant finding means that all groups tended to agree on a term, either liking or not liking it. A significant finding was discovered for the following terms:

- consumer $\chi^2(12) = 26.40, \rho < .01$
- patient $\chi^2(12) = 42.82, \rho < .001$
- stakeholder χ^2 (12) = 28.04, ρ < .01
- patron χ^2 (12) = 42.98, ρ < .001

These results illustrate that the responses differed by identity group. For example, in the medical community, practitioners commonly use the term patient. However, in this study, 62.2% of mental health providers disagreed or strongly disagreed with using the term patient, as did 42.5% of persons experiencing a mental illness. In comparison, 46.8% of family and friends tended to be more accepting of the term.

For the term consumer, while all groups tended to disagree or strongly disagree with using the term, 25.3% of individuals experiencing a mental illness were more accepting of the term in comparison to 17.7% of mental health service providers and 13.5% of family and friends. Roughly 8% more mental health service providers favoured the term stakeholder as compared to the other groups of respondents. Mental health service providers disagreed (85.5%) more strongly with the term patron, as did the other groups whose results ranged from 54.5% to 66.1%. Thus, while differences between groups existed, responses tended to cluster in the strongly disagree, disagree, and neutral category.

Qualitative Data

To manage nearly 1,000 comments of qualitative data, we looked for commonalities or themes in the responses to the open-ended questions. Themes chosen were based on observing a commonality of qualitative responses to each question. For example, the following themes emerged in relation to the question in Section II, *When I hear the word consumer I think of someone who:*

• Theme 1: Commercial/purchasing, uses something Uses a product or something up, eats, consumes Buyer, shopper

- Theme 2: Service/requires something Accesses a service or contracts a health provider, requires assistance
- Other comments: not participating, passive, powerless; better than patient, advocate

Section II of the survey asked respondents for written reactions to the words consumer, client, participant, stakeholder, and patron. Consumer was felt to be a negative term and meant using up, eating, consuming, and being too commercial or businesslike (63–68%). Client was chosen as the most favourable term in relation to someone with a mental illness who was seeking help (34–76%), although there were strong undertones of paying for a service. Stakeholder and patron were both judged to be too businesslike and financially related. Participant was generally interpreted to be a partner, or someone who participates in a team or project.

Tables 1 and 2 report the results from persons with mental illness and mental health service providers, respectively, indicating what the various labels meant to them. The majority of respondents in these two identity groups disliked the labels consumer, stakeholder, and patron. These two groups stated that participant was a more acceptable term, as in partnering with a service provider or being part of a team. Client was most accepted by mental health service providers in working with people with mental illness.

Respondents	Label	Percentage	Examples of comments				
Person experiencing	Consumer	65% 1. Using up, consuming, commercial					
or who had experienced a mental illness		21%	2. Involved in mental health system				
		14%	3. Other meanings – hiding, angry				
	Client	42%	1. Receiving health care or professional service				
		40%	2. Business, purchasing, retains a lawyer, customer				
		18%	3. Other – good word, goes with "confidently"				
	Participant	62%	1. Partner, contestant, actively involved, part of a team				
		19%	2. Health care, professional service				
		19%	3. Other – doesn't work, goes to workshops				
	Stakeholder	65%	1. Business, stocks, politics				
		29%	2. Health care, professional services, works with physician				
		6%	3. Other – going out for dinner, ambiguous word				
	Patron	59%	1. Frequents a business, bar, a customer				
		27%	2. Monetary or voluntary support				
		14%	3. Other – has been in the war				

131

 Table 1

 Qualitative Responses to Five Labels From Persons Experiencing or Who Had Experienced Mental Illness

Respondents	Label	Percentage	Examples of comments				
Mental health	Consumer	68%	1. Commercial or purchasing – to use up, eater, shopper				
service providers		14%	2. Accessing a service, contacting a care provider				
		18%	3. Other meanings – passive, advocate				
	Client	76%	1. Needing, accessing a service, paying for an expensive service				
		9%	2. Business professional				
		15%	3. Other – label, distant, arm's reach				
	Participant	67%	1. Partner with a service provider, taking part, research subject				
		27%	2. Business or sport				
		6%	3. Other – someone with serious disabilities				
	Stakeholder	47%	1. Service or programs, has an interest in the development of a service				
		43%	2. Business, bureaucracy, financial				
		10%	3. Other – sounds like a horse or stock owner, hate this term				
	Patron	47%	1. Financial support, pays money, donates				
		34%	2. Supports a business, frequents a bar, pub, store, restaurant				
		19%	3. Other – patron saints, shouldn't be used				

 Table 2

 Qualitative Responses to Five Labels From Mental Health Service Providers

For Section III of the survey, when speaking to co-workers, family or friends, or persons with mental illness, the majority of people in all four identity categories commented strongly that the preference was to use the person's name, first name, person, individual, or human when referring to a person with a mental illness. A distant second choice was to use a specific label, for example, member, friend, mentally handicapped, consumer, or the specific illness.

Suggestions in Section V for additional terms included a person's name, person, individual, and people as the preferred choice by the majority of the respondents. Other terms were survivor, member, resident, colleague, and mentally or cognitively challenged. Respondents recommended getting rid of the labels consumer and mental illness, and the slang terms crazy, nuts, and wacko.

The comments in Section VI reflected that terminology is very important, no one term is appropriate in all circumstances, and labels change too often. The language used in addressing people with mental illness could be demeaning, derogatory, and stigmatizing. People with mental illness should not be treated any differently from anyone else, and it is important to treat the whole person with respect, love, and empathy. Several respondents commented that this study was thought-provoking and worthwhile.

From the qualitative comments, it seemed evident that the respondents wished to eliminate all labels and to adopt a more sensitive manner in speaking that focuses on the person instead of the illness.

LIMITATIONS

A random sample of respondents was not attempted as anyone attending any of the sessions mentioned in the Population, Sample, and Setting section was free to answer the survey. As well, any person having access to a computer could log onto the provincial or national websites of the Canadian Mental Health Association and submit a survey.

In Section IV, relating to role identity, 233 people answered in more than one category. For purposes of the Pearson chi-square analysis, these surveys were not included, allowing an analysis of 527 people who answered in only one category.

In the qualitative response analysis, many of the 233 individuals who chose more than one category identified themselves as people who were experiencing or who had experienced a mental illness. Some mental health service providers also chose more than one category. The rationale to include these 233 individuals in the qualitative analysis was based on the desire to hear from as many respondents as possible who were experiencing or had experienced mental illness about what terms they did or did not prefer. A further rationale was to determine what terms were chosen or avoided by mental health providers.

DISCUSSION

In comparing the findings of this study to other studies that examined labels in mental health care, there are some similarities, although the types of respondents, labels, and settings differed. Table 3 compares the results of these studies. The findings indicated that when people associated with mental illness—either recipients or providers of mental health services—are given the choice between patient and client, more people choose client.

This study presented 10 terms for choices and surveyed four role categories of respondents. When explicitly asked about addressing people with mental illness, 71.1% of respondents chose individual and 51.1% chose person with a ... (specific illness). All the other terms presented in this study received much lower percentages, as did consumer and survivor in the other studies mentioned in Table 3.

Many respondents commented in writing that individuals with mental illness should be asked how they would like to be addressed. Respondents clearly stated that slang terms such as wacko, schizo, and nuts demoralize, insult, and stigmatize people with mental illness and should be eliminated. This finding is similar to that of Covell et al. (2007) and Lloyd et al. (2001) who stated that people who study and work with persons with mental illness need to acknowledge the preferences and listen to the voice of recipients of health care. Oaks (2009) reaffirmed that people with mental illness should be listened to as they have indicated strong preferences for how they prefer to be addressed.

Wing (1997) raised an important point for health care professionals when he wondered whether attitudes and behaviours might be adversely shaped by the use of a particular term. Imrie (1994) stated that the term *patient* provides a daily reminder that sick people suffer. Conversely, Atkinson (1993) believed that the term

Authors	п	Participants and setting	Patient	Client	Consumer	Survivor	Individual	Person with a (specific illness)	Participant
Mueser et al., 1996	302	Inpatients, outpatients Mental health services, U.S.	20%	45%	8%				
Sharma et al.,	550	1. Service providers	68.4%	26.5%	0.5%	7%			
2000	427	2. Recipients of mental health services Four psychiatric settings, Ontario	54.8%	28.8%	2.8%				
Lloyd et al., 2001	125	Inpatients, outpatients Mental hospital, Australia	23%	34%	28%				
Covell et al., 2007	1,827	Recipients of mental health services	22%	39%	16%	11%			
Gardiner et al.ª	760	 Mental health service providers Persons with mental illness Family, friend Other 	31.2%	47.3%	18.7%		71.1%	51.1%	23.7%

Table 3
Percentages Comparing Mental Health Studies and Preferences of Terms Chosen

Note. ^aThe table includes 6 of the 10 terms examined in our study. The remaining four terms are subject (4.8%), stakeholder (11.9%), patron (10.3%), and mentally ill (12.5%).

sufferer has a passive connotation, but that there may be long periods in their lives when sick people do not suffer nor are they patients.

The information gathered in this study provided insight germane to preferences of terms used to address individuals with mental illness. It revealed which terms are preferred or avoided. Although the goal of the study was not to recommend a favoured term, the terms individual and person with a ... (specific illness) emerged nevertheless.

Burr and Butt (2000) urged that new language be developed in mental health that would empower rather than oppress people living with mental illness. The present study acknowledged from the outset the concern that the very use of specific terms can contribute to the further stigmatization of individuals with mental illness. When given the opportunity to comment, respondents stressed that labels can be negative and stigmatizing, and it is time to treat individuals with mental illness with respect and dignity. The analyses of the data also indicated that the majority of the 760 respondents prefer not to use the terms consumer,

participant, patient, subject, stakeholder, patron, or mental illness when referring to a person with a mental illness. Respondents showed clear preferences in choices of the terms presented, and stated that labels should be eliminated. Studies have shown that when people are classified and labelled, their behaviour can actually change and therefore they are treated differently (Link, Mirotznik, & Cullen, 1991).

As a result of this work, awareness and discussion of appropriate terminology is being promoted by presentations to groups and conferences, by random conversations, and by example. Ideally, it seems that the development of a common or universal language in mental health that would result in clear, accurate, and respectful communication would be beneficial.

The participants of this study have declared their labelling preferences. They have stated that labels have meanings that can be detrimental to one's mental health. Because of the power of language, the labels used in addressing people with mental illness impact social relationships in a very significant and often negative manner. Young (2009) stated that the internalized social construction of mental illness as the definition of a person limits that person's identity. The stigma of mental illness could result in a permanent loss of self, value, and meaning. As a consequence of their research, Angermeyer and Matschinger (2003) declared that labelling has an impact on public attitudes toward people with mental illness, with negative effects clearly outweighing any positive effects. The negative effects continue to prevail in the general public's impression that people with mental illness should be feared and kept at a social distance.

CONCLUSION

Based on the evidence of this study, it is recommended that persons in the mental health field use terms with caution when referring to people with mental illness. Terms that were accepted and are still being used by mental health service providers, such as consumer, may be considered disparaging and stigmatizing. Given the conscious effort necessary to alter attitudes and behaviour, persons involved with mental health are encouraged to read the findings of this study, examine the terminology used in their area and, if necessary, adopt a more sensitive manner of speaking when referring to people with mental illness. Mental health service providers are urged to consult with the individuals they serve to learn how these people would like to be addressed.

The qualitative data strongly suggest that, in all situations, people should avoid using labels and rather use the person's name, person, or individual with a ... (specific illness). Replication of this study is recommended to determine if similar results will be discovered. Similar findings could further support the move to dispense with labels, to work toward eliminating stigma, and to treat mental illness with the same attitude as a physical illness. Examining the difficult question of how to refer to groups of individuals is also a distinct and worthwhile pursuit for further study.

RÉSUMÉ

Cette recherche descriptive exploratoire essaie de déterminer les préférences courantes et la compréhension des termes employés pour faire référence aux personnes atteintes de maladies mentales. De septembre 2005 à janvier 2006, 760 questionnaires ont été remplis à travers le Canada lors de congrès sur la santé mentale, de rencontres, sur des sites web provinciaux, et nationaux sur la santé mentale et dans des classes de collège. On a demandé aux répondants d'indiquer s'ils étaient des employés de service en santé mentale, des gens souffrant de maladies mentales, un(e) ami(e) ou un membre de la famille ou une personne qui ne correspondait à aucune de ces catégories. Des données quantitatives et qualitatives ont étions recueillies. L'analyse de ces données indique que ces répondants éprouvent une aversion aux étiquettes et une majorité des répondants préfèrent utiliser le terme individu ou le nom de la personne.

Mots clés : étiquettes, stigma, préférences, santé mentale, terminologie

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