

WORD POWER: Terminology Research in Mental Health

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INTRODUCTION TO THE STUDY:

Terminology and the stigma that is often associated with words is a prominent concern in the mental health field. The terms used to refer to persons with a mental illness who are using the public health services affect not only service providers and the individuals receiving the services, but the general public and people with mental illness as a whole. This exploratory descriptive research study was undertaken to determine the current usage and understanding of terms used in health services to refer to persons with a mental illness.

METHODOLOGY:

A six section survey, comprising both closed and open ended questions, was developed, pretested twice, and reworked several times to ensure clarity of the questions. The survey met FOIPP guidelines and received Certification of Ethical Acceptability for Research Involving Human Subjects from the Human Research Ethics Committee of Red Deer College. Participation was completely voluntary and strictly confidential.

Surveys were collected from September 2005 to the end of January 2006. Survey respondents represented adults attending the Canadian Mental Health National Conference, educational sessions of the Canadian Mental Health Association and, the Annual General Meeting of the Canadian Mental Health Association (CMHA), Central Alberta Region. Psychology students at Red Deer College also responded. Surveys were also posted on the CMHA Provincial and National websites for the months of November and December 2005 and January 2006.

A total of 760 surveys were analyzed in relation to quantitative and qualitative data. Frequencies in each question area are displayed through graphs and tables. A Chi Square analysis was conducted on 527 surveys, using the SPSS Program (version 13) to determine if an association existed between terminologies used (Section I) and the identification of roles category (Section IV). A total of 968 qualitative responses were analyzed. This data was organized into three themes for each questionnaire section, then described and interpreted.

FINDINGS:

For Section I, in rating the terms used to refer to someone experiencing a mental illness, respondents generally disagreed with the terms ***Consumer, Participant, Patient, Subject, Stakeholder, Patron*** and, ***Mentally Ill***. The respondents mostly agreed with the terms ***Client (47.3%), Person with... (specific illness)(51.1%)*** and, ***Individual (71.1%)***.

In relation to how words were perceived (Section II)

- ***Consumer:*** the majority of the respondents (82.2%) stated that they thought of someone purchasing a product or service but ***NOT*** having a physical or mental illness, requiring a service or making a choice.
- ***Client:*** the majority (84.9%) thought about someone obtaining a service.
- ***Participant:*** the majority (96.4%) thought about someone who partakes in an activity or is part of a group.
- ***Stakeholder:*** the majority (78.4%) thought about someone who has something to lose if a service is discontinued.
- ***Patron:*** the majority (73.4%) thought about someone who supports a particular cause.

In Section III, when speaking to ***co-workers***, the majority of respondents (62.4%) preferred “person suffering from a... (specific illness)” and 58.7% preferred “individual”. Only 22.6% indicated they would use “consumer” and very few would use “stakeholder (5.4%), “subject” (4.2%) or “patron” (1.2%).

When speaking to ***friends and family***, 67.4% preferred “person suffering from a... (specific illness)” and 54.3% preferred “individual”. Very few indicated they would use the terms “consumer” (14.3%), “participant” (9.5%), “stakeholder” (3.0%), “subject” (2.5%) or “patron” (0.7%).

When speaking to a ***mentally ill*** person, the highest percentage of respondents (67.8%) preferred to use the term “individual”.

Chi Square Analysis was conducted to determine if there was a significant association between the identification category (Section IV) and the words used to refer to someone with a mental illness (Section I). The total sample of 760 was reduced to 527 by eliminating any questionnaires where respondents identified themselves in more than one category. Of the 527 respondents there were 166 mental health service providers, 67 individuals experiencing mental illness, 127 family and friends and, 167 respondents who responded “other” or “none of the above”. The Chi Square analysis indicated an association between these identities and the terms of “consumer”, “patient”, “stakeholder” and, “patron”. The majority of individuals in the four identity categories strongly disagreed or disagreed with the terms “consumer”, “stakeholder” and, “patron”. The majority of mental health service providers either strongly disagreed or disagreed with the term “patient”. None of the other identity categories displayed a majority in either disagreeing or agreeing with the term “patient”.

Table 1. Section I asks: If I or someone I know were experiencing a mental illness I would prefer that I or that person be described as a *consumer*.

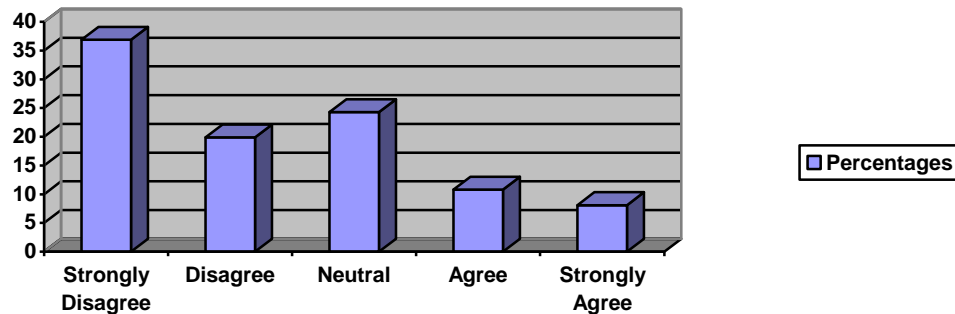
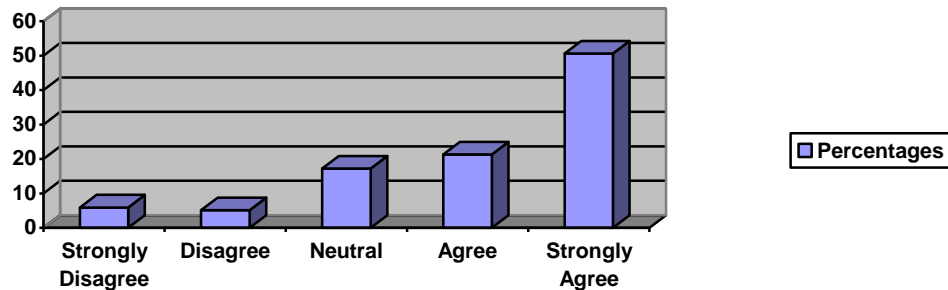


Table 2. Section II asks: If I or someone I know were experiencing a mental illness I would prefer that I or that person be described as an *individual*.



Qualitative responses from Section II were analyzed and categorized in relation to the following terms:

- **Consumer:** judged to be a negative term, means using up, eating or consuming.
- **Client:** most preferred.
- **Stakeholder, Patron:** too business and financially related.
- **Participant:** partner, team member or participating in a project.

For Section III, the majority of respondents in all four categories preferred to use an “individual’s name”, “first name”, “person”, “individual” or “human”. Additional terms that were suggested in Section V were “survivor”, “member”, “resident”, “colleague” and, “mentally/cognitively challenged”. There were several comments suggesting getting rid of the terms “consumer”, “nuts”, “wacko” and, “mental illness”.

For Section VI, there were many comments reflecting that terminology is very important and that no one term is appropriate in all circumstances and labels change too often. Labels used could be demeaning, derogatory and, stigmatizing. There were several suggestions relating to the importance of using respectful terminology and to treat people with a mental illness (and all people) with respect.

RECOMMENDATIONS:

1. Based on the findings of this study, it is recommended that persons in the mental health field use terms with caution when referring to people with a mental illness.
2. Persons involved with mental health are encouraged to read the findings of this study and examine the terminology used in their area and if necessary adopt a more sensitive manner of speaking when referring to people with mental illness.
3. Mental Health Providers are encouraged to examine the terms they use for they may be considered, by people with a mental illness, to be demeaning, derogatory, and stigmatizing..
4. Mental Health Providers are encouraged to consult with the individuals they serve to learn how people with a mental illness would like to be addressed.
5. The qualitative data strongly suggests, in any situation to avoid labels, to use the person's name, person or individual with a... (specific illness).
6. It is recommended to monitor the process of any manually completed surveys that are transposed to an on-line website to ensure that the on-line survey stays true to the original.
7. Replication of this study is recommended to determine if similar findings would be discovered.

STUDY LIMITATIONS:

1. *There was a difference in the instructions given to respondents between the manual survey and the on-line survey for completing Sections II and III. While the questions asked were identical, in the on-line survey, respondents were asked to indicate "yes" and "no" in each question area; whereas in the manual survey, respondents were only asked to circle a "yes" response. The analysis accommodated this difference in instructions. For questions in Section III, the on-line survey did not provide an "other" category. However, respondents were given the opportunity to suggest "other" terms in Section V.*
2. *In Section IV, relating to the identification category of the respondent, 233 respondents answered in more than one category. For purposes of the Chi Square Analysis, these respondent surveys were not included, allowing an analysis of 527 respondents, who only answered in one category. The categories of "none of the above" and "other" were collapsed for purposes of this analysis and the qualitative data analysis.*
3. *For the qualitative analysis in Section IV (identification) for the 233 respondents who identified in more than one category, the category of "person experiencing/had experienced mental illness" was chosen as the primary role. If more than one category was chosen, excluding "person experiencing/had experienced a mental illness", but including "mental health service provider", then "mental health service provider" was chosen as a secondary role. The rationale for this decision was that it was believed to be important to determine from as many people experiencing illness what terms they were comfortable with and also what terms are used or avoided by mental health service providers.*

**For further information, questions or comments please contact:
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