WHAT’S IN A NAME? – THE PSYCHIATRIC
IDENTITY CONUNDRUM

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SUMMARY

Background: The proper label to describe people receiving care has evoked considerable debate and controversy among
providers and bio-ethicists. Fashionable terms in current use include “patient, client, consumer, customer and service user.” There is
little evidence to show that changes in nomenclature actually take patients preferences as to how they would like to be addressed into
account

Aims: This aim of this study is to survey the views of people with learning disability in inpatient settings to establish the term
they prefer. This is the first study of its kind looking at the views of people with learning disability about how they would like to be
addressed and to identify factors associated with various preferences.

Method: Approval was obtained from the local clinical governance board. The target population covered a tertiary level
inpatient service including acute assessment and respite services, forensic (male/female and low/medium secure services) and
CAMHS LD covering the Coventry, Warwickshire and Birmingham areas (rural and inner city population). Participants were
provided with an information sheet on the research project. The questionnaire was administered by means of a joint interview
carried out by the authors of the study. Dictionary definitions were analyzed as to the derivation and connotations of various
terminologies. A questionnaire was developed which was tailored for use in PWLD after consultation with Speech & Language
Therapists and local peer review. Responses were then analyzed to identify factors associated with various preferences

Results: Evidence indicates lack of universality in preferences for terms and suggests the need for dialogue about preferred terms
between service providers and recipients. This study shows a preference for the term “patient” in all categories that were measured
within an LD inpatient setting and very interesting demographic preferences were identified. A more differentiated approach may be
suggested by taking professional background and some demographic characteristics into consideration. A positive therapeutic
relationship is a fundamental component of psychiatry and should take into account patients’ preferences regarding how they are
addressed by professionals.

Key words: patient - learning disability – customer - service user – client - consumer

INTRODUCTION

It is well recognized that a positive therapeutic
relationship is a fundamental component of the practice
of psychiatry (McGuire et al. 2001, Theoretical frame-
works for investigating and understanding the thera-
peutic relationship in psychiatry) and should take into
account patients’ preferences regarding how they are
addressed by mental health professionals. Attention to
words is essential and connotations of particular terms
have significant implications for the delivery of high
quality care.

There remains debate among providers and
recipients surrounding appropriate nomenclature to
describe recipients of health care in medical settings
(Neuberger & Tallis 1999). This can often be influenced
by bio ethicists, providers of care, human rights,
political correctness and market relationships.

The use of the term client as an alternative to patient
is becoming increasingly frequent in psychiatric settings
(Morgan 1992, Shore 1988). In learning disability
settings, there are additional terms of reference currently
in vogue especially amongst non medical staff.

Key propagators of nomenclature alternative to
patient include empowerment, involvement, active and
hopeful collaboration. Arguments against include inap-
propriate businesslike demedicalization which could
impede treatment and recovery.

What do we know so far?

Despite the current popularity of terms such as
‘client’ and ‘service user’, evidence indicates that
people prefer to be addressed as ‘patients’ and find it
much less objectionable than the other alternatives
suggested (Upton & Boer 1994, Ritchie et al. 2000,
Sharma et al. 2000, Simmons et al. 2010).

Aim

The objective of this study was to survey the views
of recipients of learning disability services to establish
the terms of address they preferred and to identify
factors that predicted their preferences.

This is the first study of its kind looking at the views
of People with Learning Disability about how they would
like to be addressed by mental health professionals.
METHODOLOGY

Participants

All in-patients at Brooklands tertiary care learning disability psychiatric hospital (Birmingham, United Kingdom) were invited to take part in the study.

Setting

The participants were housed across several units including: one respite and rehabilitation ward, eight adult assessment & treatment wards, three CAMHS LD assessment & treatment wards, one medium secure unit and seven low male/female secure wards. The geographical area covered Coventry, Warwickshire and Birmingham (rural and inner city population) with a catchment population of over two million people.

Study Design

Dictionary definitions were analyzed as to the derivation and connotations of various terminologies. (The shorter Oxford English dictionary on historical principles). A questionnaire was developed which was tailored for use in PWLD after consultation with Speech and Language Therapists and local peer review. The study was approved by the Coventry and Warwickshire Partnership NHS Trust clinical governance board. No ethical approval was deemed necessary.

Participants were provided with an information sheet on the research project. The questionnaire was administered by means of a joint interview carried out by the authors of the study. A member of nursing staff was also present to address any issues around communication difficulties and to ensure inter-rater reliability and reduce bias.

The terms of reference offered included “service user, patient, client, consumer and customer”. Other terms were excluded due to lack of endorsement and the difficulty in applying this in a LD population.

The subjects were administered a questionnaire asking them:

- What they were currently being addressed as by members of staff?
- Their choice of terminology.
- Their preference was revisited after explaining the definition and meanings of the terms and ensuring that these were understood.
- The participants’ rationale about their choice of terminology was explored.
- The participants were given an opportunity to state if they preferred different terms of address by different professionals.

The participants were surveyed about their preferences amongst these terms, and responses were analyzed to identify factors associated with various preferences. The participants’ demographic data and level of learning disability were also recorded.

Exclusion Criteria

Exclusion criteria included those who were on leave, too ill to participate in the study or had limited levels of understanding or communication (usually those with moderate to severe learning disabilities).

Table 1. Dictionary Definitions

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consumer</td>
<td>“Anyone who does or could receive psychiatric health care or services. Includes beneficiary, client, customer, eligible member, recipient, or patient”</td>
</tr>
<tr>
<td>Service User</td>
<td>“User of a type of support/clinical intervention designed to address the specific mental health needs”</td>
</tr>
<tr>
<td>Customer</td>
<td>“Current or potential buyer or user of products or services of an individual or organization”</td>
</tr>
<tr>
<td>Patient</td>
<td>“One who receives medical attention or treatment”</td>
</tr>
<tr>
<td>Client</td>
<td>“A person that seeks the advice of a professional”</td>
</tr>
</tbody>
</table>

RESULTS

There were a total of 106 in-patients at the time of the study. 69 (65%) were eligible for inclusion in the study. 50 (72%) were males and 19 (28%) were females. White British people composed the majority of ethnic background. The age ranged from 14-55 with the majority in the 19-50 range. A large proportion of participants were on some form of legal detention. Majority of participants had a Mild Learning Disability. The hospital, being a tertiary level setting, reflected participants from across the United Kingdom, with a majority from the West Midlands region.

More than twice the number felt that they were called “client” 55% vs. “patients” 23% by staff. Contrary to the general findings in other settings, the participants returned a higher initial self preference for the term “client” 47% vs. “patient” 35%. However, this was reversed after meanings of the various terms were explained with preference after explanation of terminology increasing in favour of “patient” 52% vs. “client” 23%.

When given the opportunity if participants would like to be addressed differently by different professionals, 100% stated that they would chose a single term of reference to be used by the multidisciplinary team.

There was minimal uptake of terms like “service user, consumer and customer”. 4% of the questionnaires were answered more imaginatively with participants stating that they would like to be called “customers”. 16% volunteered to be called by own name with 4% insisting on only their name to be used.
Table 2. Patient Comments

<table>
<thead>
<tr>
<th>Category</th>
<th>Patient Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service user</td>
<td>“Using the service”, “don’t know”, “because I'm a service user”, “easy to remember and nicer”, “sounds better than patient”, “interesting”, “easier to express yourself”, “no reason”.</td>
</tr>
<tr>
<td>Patient</td>
<td>“better than others”, “here for treatment”, “adult way”, “need help”, “don’t know”, “nicer sounding”</td>
</tr>
<tr>
<td>Client</td>
<td>“called client in old place”, “don’t know”, “like it”, “patient is old”, been told I’m a client”</td>
</tr>
<tr>
<td>Customer</td>
<td>“don’t like patient”, “can live normally when discharged”, “sounds better”</td>
</tr>
</tbody>
</table>

Women were twice as likely to prefer “client” than men (32% vs. 16%). Men were more likely to prefer “patient” (58% vs. 47%) & “service user” (20% vs. 10.5%) than women. Twice as many participants above 30 years of age preferred ‘client & service user’ (48% vs. 28%) as compared to those below 30 years of age.

Participants below 30 years of age preferred “patient” (66.5% vs. 45%). Afro-Caribbean & Asian participants were more likely to prefer “patient” than White British participants (73% vs. 48%). White British participants were more likely to prefer “service user & client” (45% vs. 18%).

Detained people more likely to prefer “patient” than informal participants (54% vs. 37.5%).

Table 3. Changes in preference after explanation of the terms given

<table>
<thead>
<tr>
<th>Category</th>
<th>Service user</th>
<th>Patient</th>
<th>Client</th>
<th>Consumer</th>
<th>Customer</th>
<th>Name</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>+10%</td>
<td>+18%</td>
<td>-26%</td>
<td>-2%</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>+5.5%</td>
<td>+21%</td>
<td>-31%</td>
<td>0</td>
<td>0</td>
<td>+5.5%</td>
<td>0</td>
</tr>
<tr>
<td>&lt;30 years</td>
<td>-4%</td>
<td>+25%</td>
<td>-24.5%</td>
<td>0</td>
<td>+2.5%</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>&gt;30 years</td>
<td>+16%</td>
<td>+18%</td>
<td>-25%</td>
<td>-3%</td>
<td>-3%</td>
<td>0</td>
<td>-3%</td>
</tr>
<tr>
<td>Detained</td>
<td>+6%</td>
<td>+20%</td>
<td>-25%</td>
<td>-1.6%</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Informal</td>
<td>+2.5%</td>
<td>+12.5%</td>
<td>-25%</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>B. Black</td>
<td>+14%</td>
<td>+1%</td>
<td>-15%</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>B. Asian</td>
<td>0</td>
<td>+25%</td>
<td>-50%</td>
<td>0</td>
<td>+25%</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>W. British</td>
<td>+7%</td>
<td>+19%</td>
<td>-22%</td>
<td>-2%</td>
<td>-2%</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>+6%</td>
<td>+17%</td>
<td>-24%</td>
<td>-1%</td>
<td>0%</td>
<td>+0.5%</td>
<td>+0.5%</td>
</tr>
</tbody>
</table>

Limitations

The study sample was drawn from learning disability in-patients and the results may be limited to this setting and may not necessarily extend to other clinical settings. People with limited understanding and communication were excluded. Initial preference for the term “client” may have been influenced by the terminology used by the non-medical staff on these wards and may be consistent with a study where many members of staff actively discouraged the term “patient” in favour of “client” (Morgan, 1992, Suicide prevention - Hazards on the fast lane to community care). There is acknowledgement of “information overload”. Participants may struggle to retain and understand that amount of information and therefore remember and say the point that has stood out for them, probably something that have heard more frequently. This may explain the increase in the use of the term “patient” after explanations given. Additionally, if the participants are familiar with a particular term, then this is what they will remember and say back. The effect of the medicalized environment and the doctor/nurse vs. patient expectations may also have had an influence in participants’ responses. The use and conceptualisation of the question word ‘why’ is difficult. It requires a

Figure 1. Overall results

participants chose “client” more than detained participants (37.5% vs. 21%).

We did not analyze preferences based on geography as there was not enough numbers to get a meaningful result.

Qualitative Observations - Participants’ rationale for choice of terminology

Participants were invited to make additional comments, some examples of which are highlighted below (Table 2).
higher level of understanding and complex verbal reasoning skills to generate a spontaneous answer that is not just a repetition of what has been said or explained.

DISCUSSION

The relationship between the health care provider and the individual they care for is extremely complex. Increasing commercialization and medical consumerism in the NHS is encouraging the use of a marketplace vocabulary. Terminology is largely contextually determined and any term used has powerful implications for treatment. Clinicians should evaluate carefully the attitudinal implications of using a particular term and to ensure that preferences are respected. Patients, whatever their circumstances, are most definitely “people” and professionally, one should never lose sight of the person behind the term.

There is a lack of universality in preferences of terms for users of mental health services and suggest the need for dialogue about preferred terms between service providers and recipients (Sharma et al. 2000).

This study shows a preference for the term “patient” in all categories that were measured within a Learning Disability in-patient setting. More research in different settings and using differentiated approach by taking other professional backgrounds and additional demographic characteristics into consideration is suggested.

REFERENCES


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