

BMJ Open Patient, client, consumer, survivor or other alternatives? A scoping review of preferred terms for labelling individuals who access healthcare across settings

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ABSTRACT

Objectives Use of the term ‘patient’ has been recently debated, compared with alternatives including ‘consumer’ and ‘client’. This scoping study aimed to provide an integrated view of preferred labels across healthcare contexts and countries to clarify labelling preferences of individuals accessing healthcare.

Design Scoping study.

Data sources A preliminary literature search using GoogleScholar, Medline, Embase and PsycINFO found 43 key papers discussing terminology for labelling individuals accessing healthcare services. We then used citation chaining with PubMed and GoogleScholar to identify studies discussing term preferences among healthcare recipients.

Eligibility criteria No date limits were applied, and all healthcare settings were considered. Primary research studies examining terminology preferences of individuals accessing healthcare, published in peer-reviewed journals were eligible.

Data extraction and synthesis All authors extracted data regarding preferred term and study characteristics, and assessed reporting quality of the studies using criteria relevant to our design.

Results We identified 1565 articles, of which 47 met inclusion criteria. Six articles that examined preference for personal address (eg, first name) were excluded. Of the remaining 41 studies, 33 examined generic terms (‘patient’, ‘client’, ‘consumer’) and 8 focused on cancer survivorship. Of the 33 examining generic terms, 27 reported a preference for ‘patient’ and four for ‘client’. Samples preferring ‘client’ were typically based in mental health settings and conducted in the USA. Of the eight cancer survivorship studies, five found a preference for ‘survivor’, and three ‘someone who had had cancer’.

Conclusions Overall, healthcare recipients appear to prefer the term ‘patient’, with few preferring ‘consumer’. Within general clinical and research contexts, it therefore seems appropriate to continue using the label ‘patient’ in the absence of knowledge about an individual’s preferences. Reasons for preferences (eg, familiarity, social identity) and the implications of labelling for healthcare have not been investigated adequately, necessitating future empirical (including qualitative) research.

Strengths and limitations of this study

- This is the first study to review patient preference for terminology across a range of healthcare settings.
- Because of the range of healthcare setting included, we could compare preferences between these settings, providing a comprehensive overview of the literature.
- The heterogeneity of study designs and quantitative methods precluded the possibility of conducting quantitative synthesis (meta-analysis).

INTRODUCTION

An individual who sought the assistance of a healthcare professional was once almost universally described as a ‘patient’. Various sociopolitical forces, including the commodification of healthcare and the gradual shift from the paternalistic to the patient-centred model of healthcare, have prompted debate about the use of alternative labels to describe ‘patients’. Whereas the term ‘patient’ may summon an image of a passive individual awaiting treatment, terms such as ‘client’, ‘consumer’, ‘customer’ and ‘service user’ may be more empowering, implying greater equality between participants in personal healthcare decision-making.¹

Yet alternative terms to ‘patient’ have not gained mainstream acceptance, although ‘client’ has had some dominance in social work² and psychotherapy, at least among those from humanistic traditions,³ likely stemming from Rogers’ client-centred work.⁴ Many commentaries in peer-reviewed journals and other media have addressed this issue,^{1–3 5–13} most arguing for retention of ‘patient’, but with some exceptions.^{1 8} The arguments against continued use of ‘patient’ are that its etymology implies suffering and passivity, it is characterised by an unequal relationship and a new term would more accurately reflect

today's person-centred healthcare practice.¹ Proponents for retention argue that a term's etymology need not govern its current usage,⁹ other terms introduce other problems,⁷ the therapeutic relationship is not inherently one of equality³ and the status quo need not change given the absence of a widely acceptable alternative. Others have argued that neither 'patient' nor its alternatives are satisfactory.¹⁰ Preferences within the cancer survivorship context have also been questioned, with uncertainty regarding the relative merits of labelling people 'cancer survivors', 'a person with cancer' or 'participants' within the research context.

Despite this, a paucity of research has investigated what terms of reference 'patients' themselves prefer. Nor have there been attempts to comprehensively synthesise the literature; only commentaries citing isolated empirical studies. Furthermore, empirical studies of labelling preferences have spanned a range of healthcare contexts, including social work, mental health, occupational therapy and cancer treatment, and patient preferences may differ across contexts. The fact that multiple articles addressing the issue of labelling are titled 'What's in a name?'^{12 14–17} and fail to cite one another highlights the narrow confines within which this research has been conducted.

Debate has also centred on whether terminology dictates the behaviour of actors involved, and therefore the quality of the healthcare.^{6 8} Such conclusions appear based predominantly on the authors' clinical experience with minimal reliance on empirical data (an exception is Goodyear and Parish¹⁸). Consequently, the effect of terminology in healthcare settings remains unknown. Labelling can generate stigma (both positive and negative), as suggested in a range of settings (eg, criminology, mental health). This in turn may give rise to congruent behaviours, consistent with labelling theory. Exploration of labelling preferences thus has important practical and behavioural implications. Widespread use of the term 'patient' may impede progress towards empowerment and shared decision-making; widespread adoption of the terms 'client' or 'consumer' may accelerate the commodification of healthcare. At present, evidence to support these or other possibilities is lacking.

Given the absence of resolution regarding healthcare recipients' preferred labels and the increasing prevalence of 'consumer' representative groups, an integrated review of studies is necessary to understand labelling preferences and inform consideration of appropriate labelling. A previous review conducted in the mental health context observed a preference for 'patient',¹⁹ but no review that covers other healthcare contexts has been published. Therefore, we aimed to fill this gap and conducted a scoping review of the relevant literature to examine preferred terms of healthcare recipients across a range of healthcare contexts, with clinical and theoretical applications.

METHODS

Data sources and searches

Initially, we planned to conduct a systematic search of Medline, Embase and PsycINFO, with search strategy based on a scoping search for relevant studies of terminology preferences of healthcare users and research participants. This scoping search (no date limits applied) involved (1) searching both Google and Google-Scholar using keywords *patient/consumer*, *patient/client* and *patient/client/consumer* and examining the first 100 matches for each, and (2) searching Medline, Embase and PsycINFO using *patient AND client AND consumer AND preference* (the restrictive nature of the latter search was chosen because of the very large number of results produced by less restrictive searches). We identified 43 papers on the general topic of terminology for individuals seeking healthcare (including commentaries as well as empirical studies on term preferences, only the latter of which are relevant to the present review). A comprehensive systematic search strategy (Medline, Embase, PsycINFO) from inception to 28 February 2018 developed using these keywords and Medical Subject Heading (MeSH) terms used in these papers identified an infeasible 652 006 records in Medline alone, owing to keywords and MeSH terms being varied and inconsistently applied. A random sample of 2000 records revealed no studies relevant to terminology preferences, and variants of the search strategy yielded similar results. Furthermore, some of the 43 papers were not indexed in Medline, Embase or PsycINFO. Due to the infeasibility of traditional systematic review methodology, we applied a targeted citation chain method^{20 21} to conduct a robust scoping review.^{22 23} We searched PubMed and GoogleScholar identifying articles from the reference lists of the initial 43 eligible source papers and their citing articles to identify additional literature on 28 February 2018 (updated December 2018). This collectively amassed a comprehensive, multidisciplinary collection of articles relevant to this topic. We included articles published in peer-reviewed journals discussing the terminology preferences of individuals accessing healthcare. We excluded grey literature (books, blogs, theses), discussion and commentaries to ensure conclusions were based on high-quality original research studies. No date restrictions were applied. Because of the importance of semantics in this study, only articles written in English were included. The results of this review are reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses²⁴ statement, [figure 1](#) and online supplementary appendix 1.

Study selection

All authors independently considered the potential eligibility of titles and abstracts generated by the search strategy. Full-text articles were obtained unless two or more reviewers deemed an abstract ineligible, with 10% of excluded records cross-checked. Each full-text report was assessed independently for final study inclusion. Disagreements about full-text inclusion were resolved by

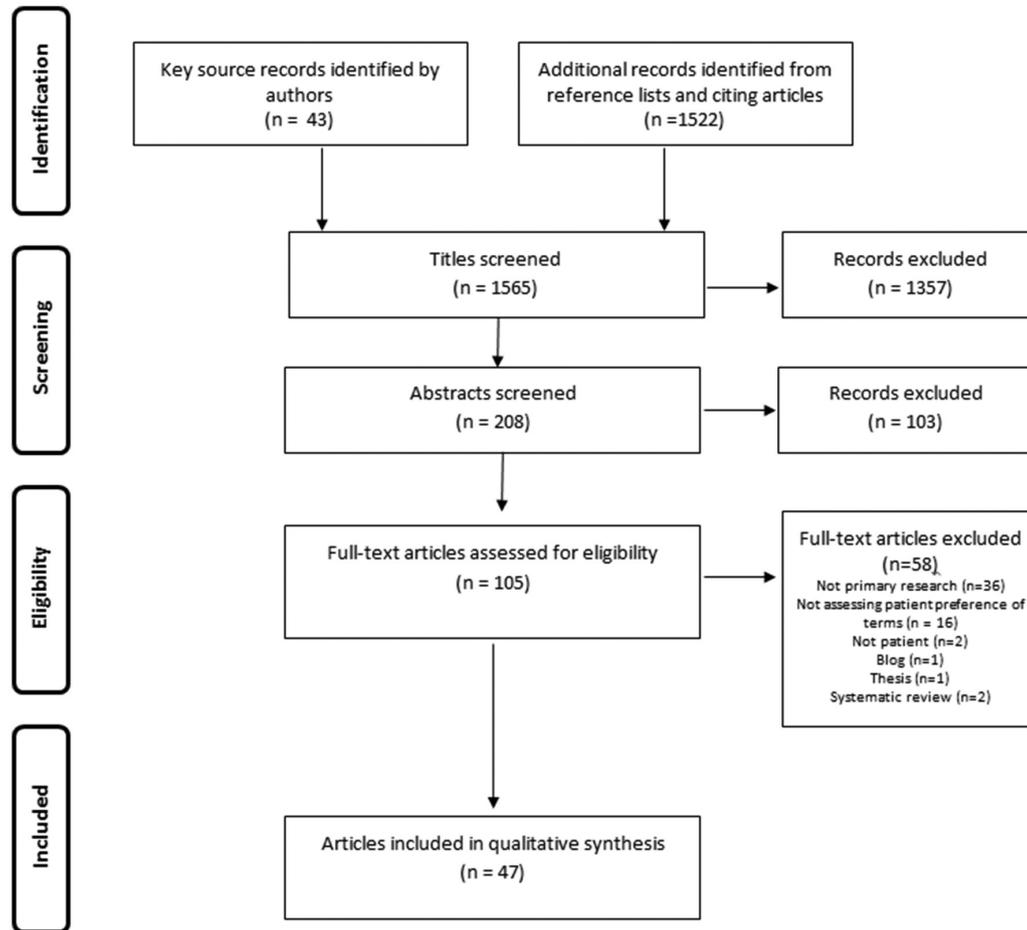


Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram.

consensus. Meta-analysis was precluded by heterogeneity in outcome variables and labels employed. Four authors (DSJC, RM-B, ST, ZS) extracted data from an approximately equal number of articles, and all authors cross-checked the extraction for accuracy and consistency. Disagreements were resolved by consensus.

Data extraction and quality assessment

The reporting quality of the reviewed studies was assessed by all authors using criteria based on selected criteria from the Strengthening the Reporting of Observational Studies in Epidemiology statement for observational and cross-sectional designs²⁵ (online supplementary appendix 2). Reporting quality assessments were conducted by a second reviewer for 10% of articles. Results of all articles were interpreted, however articles receiving a low-quality score (<25%) were excluded from secondary analyses to determine whether such studies influenced the results.

Data synthesis and analysis

For each study we examined preference, ranking or rating of each term, and determined which was most preferred. We summarised these data taking into account the specific healthcare context in which each study was conducted, and how the question was asked (including specific phrasing, if provided). We also considered year of publication and country in which the study was

conducted, as well as other variables potentially predictive of preference.

Patient and public involvement

As this is a literature review, no individuals other than the authors were directly involved in this study.

RESULTS

Our search strategy identified a further 1522 (in addition to the original 43 articles, for a total of 1565) articles. Of these, 47 met the criteria for full-text review (figure 1). The studies spanned 13 countries (20 UK, 11 USA, 6 Australia, 3 Ireland, 2 Canada and 1 each from Croatia, Israel, Italy, Korea, New Zealand, Norway, Poland and Trinidad and Tobago), published between 1990 and 2015, and covered a range of healthcare settings. Methods of preference elicitation varied across studies. Some studies asked participants how they would like to be labelled, others asked participants what they thought a particular group should be called, many studies were ambiguous on this point, and other studies did not specify the question posed. Most of the studies asked participants to nominate one or more preferred terms; fewer asked participants to rank^{26–30} or provide ratings for each term.^{28 31–33}

Reporting quality ratings of included studies

Quality ratings varied from 21.4% to 100% across studies (mean=73.9%, SD=20.0). Two studies failed to meet the quality threshold of >25%: Cybulska³⁴ and Probert,³⁵ both of which were letters to editors that reported preferences for the term 'patient'. Excluding these studies made no difference to the overall results of this review.

Summary of included studies

Eligible studies were categorised into three broad groupings. The first group (33 studies; see [table 1](#)) compared generic terms like 'patient', 'client' and 'consumer' across various healthcare contexts. The second group (eight studies; see [table 1](#)) focused on people with a prior cancer diagnosis and examined survivorship identity. Labelling preference options included 'survivor', 'someone who has had cancer', 'conqueror', 'patient' and 'victim'. The third group (six studies)^{28 36–40} focused on forms of personal address, for example, 'first name', 'last name' and 'title'. One of these studies⁴¹ examined preferences for both first/last name and patient/client/service user, and so is also one of the 33 in the first group. Only the first and second groups addressed the specific research question of preferred *terminology* in healthcare settings, hence results from only these groups (n=41) are explored in detail (see [table 2](#)). It is worth noting only that six of the seven studies^{28 36–41} examining forms of personal address indicated a preference for first name. The survivor identity studies are also reported separately given the specificity of this context, and their exclusion of certain key comparison terms (ie, terms like 'consumer' and 'client' were not given as options). The specific terms compared in each study are shown in [table 2](#).

Generic terms

Of the 33 studies that solicited preferred terms for groups of healthcare recipients, 'patient' was most preferred in 27 studies. 'Client' was most preferred in four studies. One study⁴² showed differences in preferences based on the type of health professional, whereas another study¹⁶ found that preferred term changed after terms were defined, discussed further below. A study⁴³ of women attending an antenatal clinic found 'mother to be' was preferred if the context was an information brochure, 'pregnant woman' was preferred for a medical journal or obstetrician talking to a midwife, and 'patient' was preferred when the respondent was talking to another woman. No other term was most highly rated in any of the studies, even though 'customer' (13 studies) and 'consumer' (15 studies) were commonly presented to respondents as options.

Cancer survivorship identity

Of the eight cancer survivorship identity studies, 'survivor' (five studies) and some variant of 'someone who had had cancer' (three studies) were preferred. When these options were provided, 'patient' was preferred only to 'victim'.

Personal address versus general reference

Four studies asked how participants would prefer to be addressed in person, and the remaining 37 asked about a general preference, either in relation to how the individual would like to be referred to (24, including all 8 cancer survivorship studies), how people in general should be referred to (1), and the other 12 studies were unclear, either because the questions were ambiguous or were not quoted in the article.

Contextual factors

For the 41 studies examining preferred terminology (as opposed to personal address with first name, last name, etc), the four studies that exhibited a preference for 'client' were conducted either in mental health settings (three studies) or among welfare service users (one study). In an additional study,⁴² 'patient' was preferred by respondents if told the health professional was a general practitioner, psychiatrist or community psychiatric nurse, but preference for 'patient' and 'client' were similar for psychologists and occupational therapists, and 'client' was preferred for social workers. One further study (also in mental health)¹⁶ required participants to state a preference a second time after having the meanings of the terms explained to them; after this explanation, 'patient' was preferred. Also noteworthy is that two of the four 'client'-preferring studies were conducted in the USA, compared with two of 26 'patient' preferring studies. No associations were found between preference and study characteristics in the survivorship identity studies. Year of publication did not appear to differ between studies exhibiting preference for 'patient' (median 2002, range 1990–2015) and those exhibiting a preference for 'client' (median 2004, range 1996–2008). Preferred term also did not appear to differ depending on whether respondents were inpatients, outpatients or other.

Correlates of terminology preferences

Many studies examined associations between preference and other variables. Synthesis of these results was difficult due to heterogeneity in study designs, measurement of variables and analytic methods. There was some evidence that older respondents tended to prefer 'patient' to other terms,^{14 42 44–46} although many studies found no association and some found that preference for 'patient' decreased with age.^{16 47 48} Three studies suggested that women have stronger preference for business-oriented terms, (eg, consumer, client) than men.^{16 48 49} In the survivorship studies, preference for 'survivor' was positively associated with psychological variables (eg, positive affect,⁵⁰ benefit finding,⁵¹ lower rumination⁵²), prior history of cancer,⁵³ longer time since diagnosis⁵⁴ and cancer treatment.^{52 55}

DISCUSSION

This scoping review, which spanned several countries and healthcare contexts, found that most individuals receiving healthcare preferred the term 'patient' over alternative

Table 1 Terminology preferences reported in each study

Study, country	Sample	Question/Task description*	Results	Quality total score (%)
Elliott and White, ⁴⁴ New Zealand	n=343 hospital outpatients	What would you like to be called if you were unwell and needed to be cared for by a nurse and/or doctor?	Patient 87%, client 6%, healthcare consumers 3%, other (mainly first name) 4%.	57.1
Probert, ³⁵ UK	n=100 hospital inpatients	Did they wish to be called consumers, customers, clients or patients?	Patient 96%, customers 3%, client 1%.	21.4
Cybulska, ³⁴ UK	n=36 elderly individuals in community – (also asked 18 carers)	–	Patients attending day hospital: patient 87.5%, client 6.3%, surname 6.3%. Patients visited at home by community psychiatric nurses: patient 90%, service user 5%, client 5%.	25.0
Upton et al, ⁴⁹ UK	n=85 mental health service inpatients	When you see a psychiatrist, do you think of yourself as a service user, client, customer, patient or consumer? The question was then repeated substituting word psychiatrist with psychiatric nurse and with general practitioner.	When seeing psychiatrist: patient 83%, client 7%, service user 5%, other 3%, customer and consumer 1%. When seeing psych nurse: patient 77%, client 13%, service user 4%, other 1%, consumer 2%; customer 1%. When seeing general practitioner: patient 85%, client 5%, service user 4%, customer 4%, other 1%, consumer 0%.	78.6
Batra and Lilford, ⁴³ UK	n=100 women attending antenatal clinic	Each subject was shown four separate sentences containing a blank space which could be filled in by any of the terms provided—client, consumer, maternant, mother-to-be, pregnant woman or patient.	Information brochure: mother to be 84.9, pregnant woman 70.2, patient 48.2, maternant 25.7, client 23.2, consumer 16.9. Medical journal: pregnant woman 83.0, mother to be 68.1, patient 43.6, maternant 23.9, client 14.2, consumer 7.9. Obstetrician talking to midwife: pregnant woman 69.1, mother to be 66.9, patient 61.4, maternant 23.3, client 18.4, consumer 9.4. Talking to another woman: patient 63.3, mother to be 59.3, pregnant woman 52.7, maternant 16.8, client 16.4, consumer 8.8.	41.7
Mueser et al, ⁷⁰ USA	n=302 mental health service inpatients and outpatients	We are interested in knowing what you would like to be called (other than your name) as a recipient of mental health services.	Client 44.7%, does not matter 20.5%, patient 19.9%, consumer 8.3%, other 6.6%.	64.3
Wing, ³⁰ USA	n=101 back-pain clinic outpatients	Would you prefer to be known as: a client; a patient.	Patient 74%, client 19%, no preference 8%.	58.3
Nair, ⁷⁸ Australia	n=308 radiology, emergency, pathology, medical, surgical, obstetrics and gynaecology clinic outpatient, and their companions	Subjects were asked their preference from 'a client, patient or any other title' ...	Patient 84%, client ~5%, first name ~5%, other ~4%, no response ~2%, customer ~1%.	57.1
Byrne et al, ⁷⁶ UK	n=446 antenatal clinic outpatients	...the women were asked to mark their first, second and third choice of which description they preferred for themselves, from the following list given in alphabetical order: client, consumer, customer, mother, patient, pregnant woman, woman, other (specify)	First choice: patient 39%, mother 30%, woman 11%, other 11%, client 4%, customer 1%, consumer 0%. Second/third choice: woman 26%, patient 22%, mother 20%, client 10%, customer 2%, consumer 0%.	78.6

Continued

Table 1 Continued

Study, country	Sample	Question/Task description*	Results	Quality total score (%)
Nair <i>et al.</i> , ⁷⁹ Australia	n=214 community	Participants were asked their preference of patient, client, customer or another title...	Patient 86%, client 8%, other 5%, customer 1%.	50.0
Ritchie <i>et al.</i> , ³³ UK	n=147 mental health service outpatients	The questionnaire determined subject preferences to three choices of term (patient, client or other), their attitudes (to patient and client using a 5-point Likert scale)...	Patient 77%, client 23%.	78.6
Sharma <i>et al.</i> , ⁴⁵ UK and Canada	n=977 (427 healthcare recipients; 550 providers) mental health service inpatients and outpatients	Both groups were asked their preference for one of four terms: 'client', 'patient', 'consumer' and 'survivor'. An 'other' option was also provided to allow survey respondents to provide other terms besides the four choices listed.	Recipients: patient 54.8%, client 28.8, survivor 7%, other 5.9%, consumer 2.8%.	85.7
Swift <i>et al.</i> , ⁸¹ UK and Ireland	n=145 mental health service outpatients	Patients were asked how the preferred to be addressed and how they tended to address doctors. They were asked to choose between being referred to as a patient, a client or a service user...	Patient 74%, client 18%, service user 8.3%.	85.7
Lloyd <i>et al.</i> , ⁴⁶ Australia	n=125 mental health service inpatients and outpatients	The survey asked people to place a tick beside the term that they preferred. The choices were consumer, patient, client or other.	Client 34%, consumer 28%, patient 23%, other (eg, 'mate', 'person', 'member', 'friend') 15%.	85.7
Mariotto <i>et al.</i> , ¹⁴ Italy	n=900 ambulatory care patients	What, in your opinion, is the best way to define a person attending healthcare services? Patient, client, user or other (please specify)?	Patient 61%, user 25%, client 9%, other 6%.	50.0
Ramdass <i>et al.</i> , ⁸⁰ Trinidad and Tobago	n=300 medical, surgical, gynaecological surgical and medical clinic outpatients	Subjects were asked their preference between the terms 'patient', 'client', 'customer' or 'other name'.	Patients 80%, client 7%, customer 6%, other name 7%, no answer <1%.	50.0
Baskett, ⁷⁵ UK	n=200 gynaecology and antenatal clinic outpatients	In attending this clinic which description do you prefer for yourself? (Choose one)	Gynaecological: patient 68.5%, woman 24%, client 6.5%, consumer 0.5%, customer 0.5%. Antenatal: patient 63.5%, mother 18%, pregnant woman 13.5%, woman 3%, client 2%, consumer 0%, customer 0%.	66.7
Denning <i>et al.</i> , ²⁶ Australia	n=705 antenatal clinic outpatients	The survey form offered women the opportunity to rank their preferred three choices from the following options: client, consumer, customer, female, mother, patient, pregnant woman, woman or other (specify) as title options.	Women: patient 22%, mother 16%, no response 13%, woman 12%, pregnant woman 10%, client 9%, female 8%, other 8%, customer 2%, consumer 0.5%.	100.0

Continued

Table 1 Continued

Study, country	Sample	Question/Task description*	Results	Quality total score (%)
McGuire-Snieckus et al, ⁴² UK	n=133 people in community mental health centres	<i>I would rather be addressed by a general practitioner as: (a) a patient; (b) a client; (c) a service user; (d) no preference.</i>	Preferred terms of address of the sample for each type of health professional: General practitioner: patient 75%, client 17%, service user 7%, no preference 2%. Psychiatrist: patient 67%, client 23%, service user 9%, no preference 2%. Community psychiatric nurses: patient 47%, client 43%, service user 8%, no preference 2%. Psychologist: patient 47%, client 44%, service user 10%, no preference 2%. Occupational therapist: patient 44%, client 44%, service user 13%, no preference 2%. Social worker: client 47%, patient 41%, service user 10%, no preference 2%.	92.9
Wittich et al, ⁸³ USA	n=211 obstetrics, gynaecology, family practice outpatients at army community hospital	<i>What would you like to be referred to as?</i>	Patient 84%, client 6%, healthcare consumer 4.6%, consumer 2.3%.	71.4
Aukst-Margetić et al, ³² Croatia	n=97 acute mental health service inpatients and outpatients	<i>Which of the following terms would you like us to use while talking to you during examination: patient, client, user, other? (translation)</i>	Patient 79.4%, users 13.4%, client 8.2%.	91.7
Keaney et al, ⁷⁷ UK	n=271 substance misuser inpatients and outpatients	The subject's preferences to four choices of term (patient, client, service user or other) was determined, alongside exploration of their attitudes (to patient, client and service user) using a 5-point Likert scale, from 1, 'strongly dislike' to 5, 'strongly like'.	Patient 54%, client 41%, service user 5%.	57.1
Deber et al, ³¹ Canada	n=1037 (202 breast cancer; 202 prostate disease; 202 fracture; 431 HIV/AIDS) clinic outpatients	Respondents were asked to indicate their view about being referred to as each of: patient, client, consumer, survivor, partner and customer.	Breast: patient 0.39, survivor -0.38, client -0.41, partner -0.44, consumer -0.57, customer -0.69. Prostate: patient 0.54, client -0.58, partner -0.63, consumer -0.67, survivor -0.69, customer -0.72. Fracture: patient 0.50, client -0.45, partner -0.53, consumer -0.61, survivor -0.61, customer -0.67. HIV: patient 0.48, client 0.03, partner -0.07, survivor -0.34, consumer -0.41, customer -0.49.	58.3
Covell et al, ¹⁵ USA	n=1827 mental health service outpatients	<i>Different people use different words to refer to people who have received mental health services; words like consumer, client, patient, ex-patient, survivor or some other description. What do you prefer to be called?</i>	Client 39%, patient 22%, consumer 16%, survivor 11%, other (including own name; person; human) 11% and ex-patient 1%, no answer 0.4%.	78.6
Turner et al, ⁸² UK	n=219 allied health outpatients	<i>Do you prefer to be referred to as: patient, client or customer?</i>	Patient 67%, client 30%, customer 3%.	91.7

Continued

Table 1 Continued

Study, country	Sample	Question/Task description*	Results	Quality total score (%)
Heffernan, ⁶³ UK	n=24 welfare service users	Discussion centred around two main topics: (i) current and historical terms used to refer to individuals who use(d) Health and Social Care Services and how the participants felt about these terms and/or if they identified with these terms/groups and (ii) service user involvement.	Client 42%, participant 25%, no preference 25%, service user 8%.	58.3
Simmons et al, ²⁹ UK	n=336 mental health service outpatients	Would you like a (name of discipline specified) to regard you as a service user, patient, client, survivor or user? Please rank your order of preference for the term by which you would prefer a (name of discipline specified) to regard you as.	Like: patient 72.6%, client 43.1%, service user 22.6%, survivor 14.6%, user 13.4%. Dislike: patient 11.1%, client 25.4%, service user 33.1%, survivor 45.1%, user 45.1%. Ranking: patient, client, service user, survivor.	91.7
Anczewska et al, ⁷⁴ Poland	n=1040 (634 healthcare recipients; 397 providers) mental health and social care outpatients	Its final version ... included 14 terms referring to people with mental disorders and an open category 'other – please let us know'. The participants were instructed to indicate as many preferred terms as they wished.	Patient 76.2%, person using mental health services 25.1%, person receiving psychiatric treatment 22.4%, person with mental disorders 22.1%, person with mental problems 19.2%, person with the experience of mental crisis 19.1%, person mentally ill 15.5%, person with the experience of mental illness 15.1%, person with mental illness 14.5%, attendee 13.1%, mentally ill 11.5%, client 7.4%, beneficiary 5.2%, user 3.9%, other 3.8%.	83.3
Dickens et al, ²⁷ UK	n=100 mental health service outpatients	Different people use different words to refer to people who are resident in a secure mental health service like St Andrew's Healthcare; words like client, consumer, patient and service user. What do you prefer to be called?	Patient 42%, client 20%, service user 17%, consumer 2%, other/none 19%.	100.0
Thalitaya et al, ¹⁶ UK	n=106 mental health service inpatients	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.	Thought they were called: client 55%, patient 23%. Self-preference: client 47%, patient 35%, customer/service user/consumer 4%. When terms defined: patient 52%, client 23%.	78.6
Loudon et al, ⁴⁷ UK	n=1428 sexual health service outpatients	... men and women attending sexual health clinics were asked to select the preferred description from a list including 'patient', 'client', 'customer' or 'user'.	Recipients: patient 61%, no preference 23%, client 9%, customer 2%, user 2%.	64.3

Continued

Table 1 Continued

Study, country	Sample	Question/Task description*	Results	Quality total score (%)
Sim et al, ⁴¹ Ireland	n=229 (132 healthcare recipients; 97 providers) mental health service inpatients and outpatients	...individual preferences as to how attendees are referred to by mental health staff (patient/client/service user); how attendees are addressed by mental health staff (first name/title and surname)...	Recipients: first name 86%–91%, patient 46%–54%, no pref. 92.9 20%–25%, client 14%–17%, service user 11%–13%.	92.9
Magnezi et al, ⁴⁸ Israel	n=508 general practice outpatients	A family doctor has different ways of approaching a person who comes for medical service. When you come to receive medical service from your family doctor, how do you feel s/he relates to you? Do you feel s/he approaches you mainly as: 1) a patient, 2) an insured person, 3) a friend/peer of the doctor, 4) a medical service consumer, 5) a client that deserves medical services or 6) a partner in the medical treatment. How would you like the doctor to relate to you? 1) A patient, 2) an insured person, 3) a friend/peer of the doctor, 4) a medical service consumer, 5) a client that deserves medical services or 6) a partner in the medical treatment.	Actual case: patient 45.7%, friend 21.3%, business-type term (consumer/client/insured) 20.9%, partner 12.1%. Preference: patient 40.0%, friend 28.6%, partner 18.4%, business-type term (consumer/client/insured) 13.1%.	100.0
Survivorship identity studies				
Deimling et al, ⁸⁵ USA	n=50 community-based older adults who had had cancer	Respondents were asked whether they identified as being: 1) a cancer victim, 2) a patient, 3) an ex-patient or 4) a survivor.	Survivor 90%, ex-patient 60%, victim 30%, patient 22% (survivor only 64%, victim and survivor 26%, neither 8%, victim only 2%).	83.3
Bellizzi and Blank, ⁵⁰ USA	n=490 men with prostate cancer	When you think about yourself in relation to your prostate cancer, which adjective or phrase best describes you: a patient, a victim, someone who has had prostate cancer, cancer survivor or cancer conqueror?	Someone who has had cancer 56.8%, survivor 25.9%, patient 8.8%, cancer conqueror 6.2%, victim 0.6%.	100.0
Deimling et al, ⁵⁴ USA	n=321 people who had breast, prostate or colorectal cancer	At this point in time, do you consider yourself to be: a cancer patient, an ex-cancer patient, a cancer victim or a cancer survivor?	Survivor 86%, ex-patient 42%, victim 13%, patient 13%.	64.3
Park et al, ⁸⁴ USA	n=167 adults diagnosed with cancer	When you think about yourself in relation to your cancer, how much does each of these phrases describe you?	survivor 83%, someone with cancer 81%, patient 58%, victim 18% (percentages are for those who responded at least somewhat).	100.0

Continued

Table 1 Continued

Study, country	Sample	Question/Task description*	Results	Quality total score (%)
Kelly <i>et al.</i> ⁵³ USA	n=201 individuals with a personal history of cancer	Participants were asked if they considered themselves to be a cancer patient, a cancer victim, an ex-cancer patient, a cancer survivor or none of the above.	None of the descriptors 70.5%, cancer survivor 22.5%, cancer patient 6%, ex-cancer patient 4%, cancer victim 2.5%.	78.6
Chambers <i>et al.</i> ⁵¹ Australia	n=786 people diagnosed with cancer	...a single question asked participants how they would describe themselves in relation to their bowel cancer with five possible options: a cancer patient; a cancer survivor; a cancer victim; a person who has had (or has) cancer or other.	Cancer survivors 55.0%, persons who had had (or have) cancer 39.4%; cancer patients 1.4%, victims 1.2% (missing 3.0%).	85.7
Morris <i>et al.</i> ⁵² Australia and USA	Study 1 n=514 men diagnosed with prostate cancer Study 2 n=160 women diagnosed with breast cancer	<i>When you think about yourself in relation to your cancer, which of the following phrases best describes you?</i>	Study 1: person who has/had cancer 53.1%, cancer survivor 35.0%, cancer patient 6.2%, victim 1.9%, other 2.1% (missing 1.7%). Study 2: cancer survivor 44%, person who has/had cancer 42%, cancer patient 6%, cancer victim 2%, other 6%.	85.7
Cho and Park, ⁵⁵ USA	n=133 (baseline) people diagnosed with cancer during late adolescence and young adulthood; n=88 1 year later	Six types of cancer-related identities were included: victim, patient, someone who has had cancer, survivor, cancer conqueror and member of the cancer community. Each identity was assessed as the extent to which it describes them from 0 (not at all) to 4 (very much).	Baseline: someone who has had cancer 75.0%, member 59.2%, survivor 55.0%, patient 50.8%, cancer conqueror 35.0%, victim 6.7%. One year: someone who has had cancer 77.4%, survivor 61.4%, member 56.6%, patient 44.0%, cancer conqueror 34.9%, victim 3.6% (percentages are for those who responded at least quite a bit).	85.7

*Text in the 'Question/task description' column in italics indicates the specific wording of the question, whereas plain text indicates the description of the question provided by the article.

Table 2 Terms compared within each included study

Study, country	Patient	Client	Consumer	Service user/user	Customer	Survivor	Person seeking healthcare	Person with condition*	Other term/s
Anczewska <i>et al.</i> , ⁷⁴ Poland	x [¶]						x	x	x
Aukst-Margetić <i>et al.</i> , ³² Croatia	x [¶]	x							x
Baskett, ⁷⁵ UK	x [¶]	x	x		x				x
Batra and Lilford, ⁴³ UK	x	x	x					x	x [¶]
Byrne <i>et al.</i> , ⁷⁶ UK	x [¶]	x	x						x
Covell <i>et al.</i> , ¹⁵ USA	x	x [¶]	x			x			x
Cybulska, ³⁴ UK	x [¶]	x	x	x					x
Deber <i>et al.</i> , ³¹ Canada	x [¶]	x	x		x				x
Denning <i>et al.</i> , ²⁶ Australia	x [¶]	x	x		x			x	x
Dickens and Picchioni, ¹⁹ UK	x [¶]	x	x				x		x
Elliott and White, ⁴⁴ New Zealand	x [¶]	x	x						x
Heffernan, ⁶³ UK		x [¶]		x					x
Keaney <i>et al.</i> , ⁷⁷ UK	x [¶]	x		x					
Lloyd <i>et al.</i> , ⁴⁶ Australia	x	x [¶]	x						
Loudon <i>et al.</i> , ⁴⁷ UK	x [¶]	x	x						x
Magnezi <i>et al.</i> , ⁴⁸ Israel	x [¶]	x	x						x
Mariotto <i>et al.</i> , ¹⁴ Italy	x [¶]	x		x					x
McGuire-Snieckus <i>et al.</i> , ⁴² UK†	x [¶]	x		x					x
Mueser <i>et al.</i> , ⁷⁰ USA	x	x [¶]	x						x
Nair, ⁷⁸ Australia	x [¶]	x			x				x
Nair <i>et al.</i> , ⁷⁹ Australia	x [¶]	x			x				x
Probert, ³⁵ UK	x [¶]	x			x				
Ramdass <i>et al.</i> , ⁸⁰ Trinidad and Tobago	x [¶]	x			x				x
Ritchie <i>et al.</i> , ³³ UK	x [¶]	x							
Sharma <i>et al.</i> , ⁴⁵ UK and Canada	x [¶]	x	x			x			
Sim <i>et al.</i> , ⁴¹ Ireland	x	x		x					x [¶]
Simmons <i>et al.</i> , ²⁹ UK	x [¶]	x		x		x			
Swift <i>et al.</i> , ⁸¹ UK and Ireland	x [¶]	x		x					

Continued

Table 2 Continued

Study, country	Patient	Client	Consumer	Service user/user	Customer	Survivor	Person seeking healthcare	Person with condition*	Other term/s
Thalitaya <i>et al.</i> , ¹⁶ UK‡	x¶	x¶	x	x	x				
Turner <i>et al.</i> , ⁸² UK	x¶	x			x				
Upton <i>et al.</i> , ⁴⁹ UK	x¶	x	x	x	x				x
Wing, ³⁰ USA	x¶	x							
Wittich <i>et al.</i> , ⁸³ USA	x¶	x	x						x
Survivorship studies									
	Patient	Ex-patient	Person/someone who has had cancer	Cancer conqueror	Survivor/Cancer survivor	Victim	Someone with cancer		Other term/s
Bellizzi and Blank, ⁵⁰ USA	x		x¶	x	x	x			
Chambers <i>et al.</i> , ⁵¹ Australia	x		x		x¶	x			
Cho and Park, ⁵⁵ USA	x		x¶	x	x	x			
Deimling <i>et al.</i> , ⁵⁴ USA	x	x			x¶	x			
Deimling <i>et al.</i> , ⁸⁵ USA	x	x			x¶	x			
Kelly <i>et al.</i> , ⁵³ USA	x	x			x	x			None of the descriptors¶
Morris <i>et al.</i> , ⁵² Australia and USA§	x		x¶		x¶	x			x
Park <i>et al.</i> , ⁸⁴ USA	x		x		x¶	x			x

*Includes 'pregnant woman'.

†'Patient' preferred in all subgroups except social workers ('client' preferred); for occupational therapists, 'patient' and 'client' were equally most preferred.

‡'Client' preferred before terms were defined, 'patient' preferred after terms were defined.

§'Person who has/had cancer' preferred by patients with prostate cancer (study 1), 'cancer survivor' preferred by patients with breast cancer (study 2).

¶Term was most-preferred in this study.

terms. 'Consumer' was not the overall preferred term in any study. Studies conducted in the cancer survivorship context indicated that individuals preferred the term 'survivor' and 'someone who had had cancer' over 'patient' and 'victim'. Predictors of terminology preferences varied across studies and contexts.

These results suggest that the preference for the term 'patient' has persisted over time despite the movement towards person-centred care, shared decision-making and the commodification of healthcare, which might lead us to expect a growing preference for terms like 'consumer' and 'client'. Although a large body of research demonstrates that preferences are complex and determined by both affective and cognitive factors,^{56 57} a robust and replicated empirical result within social psychology is the *mere-exposure effect*, in which an entity becomes preferred by an individual solely because the individual has had greater exposure to it.^{58 59} Thus, this strong preference for 'patient' may arise because of its familiarity to individuals seeking healthcare. One possible explanation for the *mere-exposure effect* is that repeated pairing of a stimulus (eg, the label 'patient') in the absence of an aversive outcome results in a classically conditioned response.⁵⁹ Hence, switching to a less familiar term may introduce uncertainty, for example, with a change in terminology signifying a potentially undesirable change in healthcare delivery or approaches.

Similarly, Hoyt³ described the common usage of 'client' within humanistic approaches to healthcare (prompted by Rogers' client-centred approach to psychotherapy⁴), whereas 'patient' appears more popular in medical and psychoanalytic disciplines. Consistent with this and the findings of Dickens and Picchioni,¹⁹ the four reviewed studies indicating a preference for 'client' were set in either mental health contexts or among welfare service users (although several other mental health studies did indicate a preference for 'patient'). Preferences are thus likely to be both contextually and individually determined.

Evidence also indicates that preferences are constructed in the elicitation process.⁶⁰ That is, stated preferences are sensitive to methods through which they are obtained. Individual preferences may thus (at least in part) be determined by the framing of questions and may function to elicit a preference for those who might otherwise be impartial. Heterogeneity was apparent in the phrasing of questions in the reviewed studies, the most notable difference being whether the question asked for preferences of general reference or direct address (discussed further below). Questions were often vague or ambiguous in this respect; with such crude data, we can only speculate about the processes participants used in reporting preferences. The study by Thalitaya *et al*¹⁶ is notable because spontaneous preference for 'client' was replaced with 'patient' once definitions of each were provided to participants. Individuals may thus intuitively prefer familiar terms, but alter their preferences when challenged to consider more deeply, an effect consistent with dual-processes (ie, intuitive vs deliberative) theory.^{61 62}

Preference for terminology may also be indicative of something more stable and fundamental, such as the individual's identity or perceived social role. 'Client' was preferred over 'patient' by welfare service users⁶³ and individuals seeing social workers, but not occupational therapists.⁴² Welfare and social work may not be perceived as traditional physical healthcare contexts, so individuals seeing professionals in these fields may not consider themselves 'patients'. The same may apply to mental health settings. This suggests the possibility that the same individual in different healthcare contexts (eg, traditional physical health vs mental health, acute vs chronic care) may represent different social roles. Role theory⁶⁴ argues that social roles are guided by social norms, are often reciprocal, as in the dyad of individual seeking healthcare and their health professional⁶⁵ and an individual may have multiple roles in different settings. Biddle⁶⁶ argued that preferences are reflective of role expectations. Similarly, according to social identity theory,⁶⁷ an individual's sense of identity is at least partly determined by their group membership and may vary across settings (eg, the healthcare context).⁶⁸ Individuals consulting with occupational therapists, like those who have ceased active treatment for cancer, may no longer consider themselves 'patients' and may more readily identify with some other label.

Parsons' concept of the 'sick role',⁶⁹ in which illness is considered sanctioned social deviance entailing certain rights and obligations, is particularly relevant. The emergence of the patient-centred model of care and consumerism in healthcare accompanied a decline in popularity of the 'sick role' concept. Because the concept of 'patient' is more congruent with the sick role than 'client' and 'consumer', one might expect preference for the term 'patient' to have declined over time. That our results provided no evidence for this may be explained by what role theory (specifically, interactional role theory) has to say about changing roles.⁶⁴ Social pressures can lead to changes in roles, but certain conditions are required to facilitate such change, including a unified desire for change among the actors. Perhaps preference for 'patient' has resisted change because the push for change has come from sources other than the individuals seeking healthcare themselves.

Despite the rise of 'consumer representative networks', the negligible preference for the term 'consumer' (despite 15 studies providing this term as an option) may reflect a misalignment of the consumer movement with the desires of most individuals seeking healthcare. It would be instructive to examine preferences in patient advocacy settings (both in research and clinical applications) to determine if the term 'consumer' is in fact more acceptable within these networks. Furthermore, although labelling preferences were relatively clear across studies, the practical significance of how much terminology and its meaning matters to respondents is unclear. Only Mueser *et al*⁷⁰ addressed this, finding that approximately one-fifth of respondents selected 'does not matter' (although note that their question does not distinguish between personal

address and general reference). Future research should explore this issue by asking respondents about the importance and meaning assigned to labels, and whether labelling influences quality of care provided.

Preferences may also vary cross-culturally. For example, the proportion of US-based studies exhibiting a preference for 'client' over 'patient' was larger than for other countries. Although this conclusion requires caution given most US-based studies reviewed were from mental health contexts, it suggests possible cultural differences in terminology preferences, warranting further investigation.

For research reporting purposes, whether preferences vary when directly addressing an individual as opposed to referring to the individual or labelling collectively is unclear. For example, in some studies 'first name' was nominated by participants in open-ended 'other' response options, implying that the participant interpreted the question as asking about personal address. Further, labelling context may impact preferences (as described above). Clearly, researchers do not intend that health professionals personally address an individual in a clinical setting as 'patient' instead of their name, or that published articles name each participant rather than using a collective label. Some studies were clear regarding the context in which terms would be used, either by making this explicit in the question (eg, "*I would rather be addressed by a general practitioner as...*"⁴²) or providing alternative contexts. A notable example of the latter is Batra and Lilford,⁴³ who found that preferred term depended on whether it would be used in an information brochure or medical journal, or in conversation involving health professionals or the respondents themselves.

The present review represents a critical first step in examining and delineating labelling preferences, and provides a basis for future research regarding cross-cultural and contextual applicability of labelling preferences, as well as the meaning assigned and importance of terminology preferences. Further research, particularly qualitative research, is warranted. The question of why certain individuals prefer certain terms has received very little attention (although Dickens *et al*²⁷ and Simmons *et al*²⁹ reported some qualitative explanation for preference). A more difficult but important question is whether labelling has behavioural implications for how healthcare recipients are treated and the quality of care received. There is evidence in the mental health setting that labelling behaviour as 'deviant' can have negative impact on the labelled individuals.⁷¹ Experimental approaches to this issue may have utility, with evidence suggesting that labels attached to individuals may foster attitudinal biases.¹⁸ If, for example, the term 'consumer' was to gain wider usage, would this prompt a further move towards treating consultations with a healthcare professional more like service encounters,^{72 73} and if so what are the further implications? Alternatively, would rejection of all terms but 'patient' return healthcare to the paternalistic model? With data currently unavailable, we can

only speculate on such possibilities, necessitating further research building on the present study.

Limitations of the present review include heterogeneity in the study designs and outcome variables, which precluded a systematic review and meta-analysis. We also chose not to exclude studies conducted with non-English-speaking participants, introducing potential issues regarding comparability between translated labels. We deemed, however, that the utility of the information provided by these studies outweighed any problems of translation and meaning, particularly given that such problems are less likely for single terms than phrases, and that differences across English-speaking countries may be as large as language differences. Strengths of this review include the breadth of healthcare contexts and study designs included, increasing ecological validity.

In conclusion, the findings of this research may be applied in both clinical and research contexts through continued use of the term 'patient', when knowledge about a particular individual's preferred label is lacking. We speculate that preference is partially determined by familiarity, social identity, the context of the role (eg, specific healthcare setting) and the preference elicitation method. These possible factors entail specific testable hypotheses that can be subjected to empirical examination, and the behavioural implications of labels used is crucial to determining whether labelling impacts the healthcare of individuals.

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