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Guidelines as rationing tools: a qualitative analysis of psychosocial patient selection criteria for cardiac procedures

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Abstract

Background: Cardiac procedure guidelines often include psychosocial criteria for selecting patients that potentially introduce social value judgements into clinical decisions and decisions about the rationing of care. The aim of this study was to investigate the terms and justifications for and the meanings of psychosocial patient characteristics used in cardiac procedure guidelines.

Methods: We selected English-language guidelines published since 1990 and chapters in textbooks published since 1989. These guidelines amalgamated multiple sources of evidence and expertise and made recommendations regarding patient selection for specific procedures. A multidisciplinary team of physicians and social scientists extracted passages regarding psychosocial criteria and developed categories and conceptual relationships to describe and interpret their content.

Results: Sixty-five papers met the criteria for inclusion in the study. Forty-five (69%) mentioned psychosocial criteria as procedure indications or contraindications. The latter fell into several categories, including behavioural and psychological issues, relationships with significant others, financial resources, social roles and environmental circumstances.

Interpretation: Psychosocial characteristics are portrayed as having 2 roles in patient selection: as risk factors intrinsic to the candidate or as indicators of need for special intervention. Guidelines typically simply list psychosocial contraindications without clarifying their specific nature or providing any justification for their use. Psychosocial considerations can help in the evaluation of patients for cardiac procedures, but they become ethically controversial when used to restrict access. The use of psychosocial indications and contraindications could be improved by more precise descriptions of the psychosocial problem at issue, explanations regarding why the criterion matters and justification of the characteristic using a biological rationale or research evidence.

In 1994, the Canadian Medical Association noted that "clinical practice guidelines ... can greatly assist physicians, patients, and the health care system in identifying core and comprehensive health care services." Whereas Canadian clinicians are familiar with the critical appraisal of guidelines as clinical tools, ²⁻⁴ policy analysts and ethicists have also begun to explore the implications of guidelines as administrative and rationing tools.⁵⁻⁹

Guidelines for cardiac procedures typically include patient selection criteria, which are often expressed as indications and contraindications, ¹⁰ for either tests or treatment. Biomedical selection criteria are common in such guidelines, and psychosocial criteria are increasingly being included. These psychosocial selection criteria can introduce value judgements into allocation decisions made by clinicians. The distributive effects of such "micro" decisions at the bedside are not trivial

when viewed from the "macro" level as rationing policies. Evaluations by committee of cardiac surgery candidates in the United Kingdom invoke the issue of patient "deservingness" along with discussions of lifestyle habits and other contraindications.¹¹ Finnish clinicians have found that hypothetically rationing care will generally favour children and disadvantage individuals with dementia or self-inflicted disease.¹² Transplant providers vary remarkably in their use of psychosocial criteria to select organ recipients.¹³⁻¹⁶

What are the labels and justifications for and the potential meanings of the psychosocial patient characteristics invoked by practice guidelines for a variety of cardiac procedures? We analyzed the content of practice guidelines using qualitative methods and discuss the implications of our findings for the fair allocation of cardiac procedures.

Methods

We searched for articles containing recommendations regarding patient selection that reviewed and integrated multiple sources of evidence or expertise.¹⁷ These included practice guidelines, statements made by professional societies, narrative reviews, systematic reviews and chapters of medical textbooks. These types of document both affect and reflect clinical beliefs and practices. We did not impose restrictions based on the quality, style or authority of the recommendations. We excluded articles concerning pharmacotherapy, prevention, emergency procedures, life-support, administrative interventions, "experimental" procedures and organ procurement. We also excluded guidelines that addressed unrelated issues, such as how (as opposed to whether) to use a procedure or concerning the management of cardiac diseases (i.e., how to choose among procedures for patients with a given condition, as opposed to how to choose among candidates for a given procedure).

We identified English-language guidelines published since 1990 and chapters of textbooks published since 1989 using MED- LINE and HSTAR, reference bibliographies and queries to colleagues in cardiology. For the electronic searches, we applied the following terms: "guidelines," "practice guidelines" and "consensus development conferences," crossed with any of the following MeSH headings: "heart," "heart surgery," "coronary disease" or the following text words: "cardi*," "cardiac AND surgery" or "coronary AND disease." Title screening and selection were done in duplicate. Where there was disagreement, the article was retrieved for closer investigation. Sixty-five papers were included.¹⁸⁻⁸² Forty-five (69%) papers mentioned psychosocial criteria as either indications or contraindications for a cardiac procedure (Table 1).

Two pairs of investigators (1 physician and 1 social scientist in each case) read each guideline, judged its appropriateness for inclusion and identified passages concerning psychosocial criteria. These passages were defined initially as concerning selection criteria that were not strictly physiological or biomedical in nature. The full research team reviewed the abstracted passages and developed the coding scheme. Key themes and conceptual relationships were developed following basic tenets for the interpretive analysis of documents⁸³ and grounded theory development.⁸⁴ The findings were corroborated using multiple data sources and investigator consensus.⁸⁵ This interpretive analysis describes the nature of psychosocial issues generally as they arise in many different cardiac guidelines. Our purpose was not to critique guidelines regarding their quality; to avoid such implications, we cite specific guidelines by alphabetical letter only.

Results

Categories of psychosocial characteristics

Psychosocial criteria as described in cardiac procedure guidelines fall into the following categories: behavioural and psychological issues, relationships with significant others, financial resources, social roles, environmental circum-

Table 1: Psychosocial criteria for patient selection in clinical practice guidelines

Practice guideline	Subject of guideline							· · · · · · · · · · · · · · · · · · ·
	Cardiac catheter*	Heart transplant	Implant defib	Coronary bypass	Pacemaker	Other test†	Other intervention‡	Total
With PSC	12	9	5	4	3	4	0	37
Behavioural and psychological issues	7	9	4	4	2	2	0	28
Significant others	2	7	2	1	0	0	0	12
Financial resources	2	6	3	2	2	1	0	16
Social roles	2	1	1	1	1	2	0	8
Environmental circumstances	5	1	1	1	2	0	0	10
With ambiguous PSC	4	1	0	1	0	1	1	8
Without PSC	7	0	3	2	1	3	4	20
Total no. of guidelines§	23	10	8	7	4	8	5	65

Note: Cardiac catheter = cardiac catheterization, implant defib = implantable defibrillator, PSC = psychosocial criteria.

*Cardiac catheterization includes both diagnostic catheterization and therapeutic catheterization (e.g., angioplasty, coronary artery stents).

†Other diagnostic tests include echocardiography, radionuclide imaging, ambulatory electrocardiographic monitoring, cardiac exercise testing, perioperative transesophageal echocardiography and electrocardiography.

‡Other interventions include cardiothoracic surgery, percutaneous intra-aortic balloon pump and ventricular assist devices, cardioversion and defibrillation, and surgical treatment of cardiac arrhythmias.

§Some guidelines address more than one category of psychosocial selection criteria.

stances and "ambiguous" criteria with both psychosocial and biomedical content.

Behavioural and psychological issues

Twenty-eight (43%) of the guidelines suggest that the psychological or behavioural characteristics of the patient should be considered when determining eligibility. Guidelines often use nonspecific terms such as "attitude" or "potential social and behavioural problems": for example, "it is imperative to establish a patient's psychological stability" (heart transplant guideline A), and "attention must be given to the general medical, emotional, and mental state of the patient ... before proper decisions with respect to pacing can be made" (pacemaker guideline B). Sometimes guidelines use more specific terms such as "depression" or "psychiatric illness such as schizophrenia." However, these criteria usually appear without reference to why they are important or how the assessments should be made. Previous or current substance use may be a contraindication: for example, "it is imperative to ... rule out any dependencies on drugs, cigarettes, alcohol, or compulsive eating habits" (heart transplant guideline A). Guidelines vary in the language used to describe substance abuse, from more specific terms such as "tobacco" to vaguer terms such as "substances."

Compliance with care plays a major role in defining candidacy for certain procedures (e.g., heart transplantation). Some guidelines focus on evidence of prior compliance: for example, "although an adequate psychological instrument to test compliance has not been universally accepted, compliance with a rigorous treatment regimen for congestive heart failure may be objective evidence of the patient's suitability for transplantation" (heart transplant guideline C). Other guidelines focus on purported predictors of compliance: for example, "potential risk factors for noncompliance include previous substance abuse, mood and personality disorders and inadequate family support" (heart transplant guideline D), or "good candidates must ... demonstrate emotional maturity and stability as well as a willingness to comply with the follow-up regimen" (implantable defibrillator guideline E). Such predictors mentioned in the guidelines include psychosocial problems, the candidate's skills, and the candidate's ability to comply or expressed commitment to comply.

Relationships with significant others

Twelve guidelines (18%) refer to the candidate's relationships with others as a criterion for selection. These others may have a specific relationship to the candidate (e.g., caregiver, parent) or may represent more abstract structures (e.g., family unit, social support): for example, "besides diagnosis and age, factors that affect the decision include the reliability of the parents or guardians who take the patient home" (cardiac catheterization guideline F), and

"it is important to assess the patient's ... psychosocial support system ... a strong supportive family unit is of immeasurable value in tiding the patient over the rigors of the postoperative period" (heart transplant guideline G).

Significant others are portrayed in various roles in relation to the intervention itself. They may be considered a necessary adjunct to treatment (e.g., ensuring compliance or providing care at home): for example, "the social, emotional, intellectual, and financial stability of the care provider must be assessed in the preoperative and postoperative periods" (heart transplant guideline C). Alternatively, significant others are sometimes portrayed as indirectly benefiting, or suffering, from the candidate's intervention and thereby are factored into the candidacy assessment: for example, "because post-transplant management is complex, difficult, and potentially disruptive to the family unit, certain medical and social criteria must be met by the candidate and family" (heart transplant guideline H), and "improvement of quality of life can, for example, be described in terms of [among other things] ... relief of anxiety of patients, partners, and relatives" (implantable defibrillator guideline I).

Financial resources

The candidate's financial resources are identified in 16 (25%) of the guidelines as a selection criterion. At issue is either the candidate's ability to pay for the procedure itself, or to pay for support services: for example, "the transplant candidate's family must have the means to cover expenses related to the pre-transplant evaluation and waiting period, transplant procedure and hospitalization, and long-term care, including medications" (heart transplant guideline H). Some guidelines refer more vaguely to the expense of the procedure or to issues such as "societal resources." Specific recommendations regarding patient selection are not given, but cost sensitivity is highlighted as a consideration: for example, "the primary reason not to perform echocardiography in many cases is economic. The cost-effectiveness of echocardiography in these settings is related to the individual case. Societal resources must be considered by the physician" (echocardiography guideline J). Many of the guidelines were written by US health care providers concerned with patients' insurance status and their ability to pay for care; however, issues such as the ability to pay for adjunct services (e.g., drugs, travel) and the burden on societal resources apply in the context of Canada's universal health insurance as well.

Social roles

Sometimes candidates' social roles, particularly their occupation or their ability to perform a job, qualify them for cardiac procedures. Guidelines justify these occupational selection criteria on the grounds that certain workers face exceptional physical demands and, therefore, require special diagnostic attention or access: for example, "evaluate patients of any age who are in special occupations that require very high cardiovascular performance (e.g., fire fighters, police officers, astronauts) or whose cardiovascular performance is linked to public safety (e.g., pilots, air traffic controllers, critical process operators, bus or truck drivers and railroad engineers)" (electrocardiography guideline K).

Environmental circumstances of the candidate

The environmental circumstances of the candidate are sometimes portrayed as eligibility criteria. Such criteria include candidates' geographic proximity to health care providers, their ability to travel to access these services or their need to travel as part of their occupation: for example, "general criteria for exclusion from ambulatory catheterization [include] [g]eographic remoteness (more than 1 hour drive) from the laboratory with inadequate or unreliable follow-up likely over the next 24 hours" (cardiac catheterization guideline F).

Psychosocial and biomedical criteria

Some patient selection characteristics can be understood as either "psychosocial" or "physical," or both. Such dual criteria in the guidelines we reviewed included age, life expectancy, sex, reproductive status, body weight, obesity, disability, function, activity levels, quality of life and lifestyle.

Interpretation

Guideline authors use psychosocial criteria to describe a range of nonbiomedical issues that pertain to patient selection for cardiac procedures. These include patients' behaviour, mental state, relationships with other people, financial resources, role in society and their environment. Such factors can be clinically important for evaluating patients holistically, for understanding their special needs and capacities, and for considering the potential risks and benefits of a procedure. However, these same psychosocial characteristics become ethically controversial when they are used to determine individuals' access to scarce technologies that are in great demand. We need to understand better the reasoning behind psychosocial criteria and reconsider their implications for distributive justice if guidelines are to be used to direct and control resource use.

The format in which psychosocial criteria for patient selection are presented in guidelines may also affect their interpretation and application. Guidelines typically simply list psychosocial contraindications, without clarifying the nature of the particular psychosocial issue. Guidelines rarely discuss the psychosocial concern or cite the biological, evidential or authoritative rationale for including it. Very few guidelines discuss the controversy surrounding particular psychosocial indicators, explain psychosocial criteria on

pathophysiological grounds or include specific recommendations for objectively assessing the presence or degree of a psychosocial characteristic. Not surprisingly, the few guidelines that do discuss these issues come from the field of cardiac transplantation, in which heightened sensitivity about equity and fair distribution of scarce organs exists.⁸⁶

We found that developers of guidelines tend to portray a psychosocial characteristic as playing 1 of 2 roles in patient management: as a risk factor intrinsic to the candidate or as an indicator of need for special intervention. These different ways of portraying the role of psychosocial characteristics have implications for both clinical actions at the bedside and distributive justice at the social level. A framework for understanding the ethical imperatives is available elsewhere;⁸⁷ we briefly review and illustrate the key issues here.

Some guidelines declare that individuals with a given psychosocial characteristic are poor candidates or ineligible for the intervention: for example, "while a child should not be deprived of the potential benefit of cardiac transplantation because of a situation beyond his or her control, a precious donor organ should not be squandered if failure is inevitable because of an adverse psychosocial situation" (heart transplant guideline L). Psychosocial features thus may be promoted as a way to select candidates based on the assumption that people without the problem will do relatively better and thus yield more health per procedure. The underlying utilitarian reasoning dictates that society should allocate resources where they will produce the most health for the community as a whole and, thus, patients with more modest benefits become lower priority candidates. This reasoning may also motivate institutions seeking to demonstrate superior outcome statistics: for example, "consistent objective criteria for patient eligibility are necessary to prevent 'program shopping' by patients with the resources to do so and 'candidate shopping' by programs looking for the lowest postoperative mortality statistics, which may be achieved by performing a transplant procedure in those patients who need it least" (heart transplant guideline D). In cases where the procedure would actually harm the person with a psychosocial contraindication, the utilitarian rationale may be accompanied by the familiar clinical ethic of nonmaleficence: for example, "tobacco use before heart transplantation will likely continue after heart transplantation and increase morbidity and mortality. A history of alcohol and drug abuse should be carefully evaluated; recidivism after heart transplantation may be fatal" (heart transplant guideline N).

However, psychosocial problems are not always portrayed in a utilitarian spirit. Some guidelines recommend treatment for the psychosocial contraindication as either an adjunct or prerequisite to the cardiac intervention. In certain cases, a patient's living circumstances may require special accommodation on the part of the health care provider: for example, "only a small number of patients will have the support system required to closely monitor symptoms after the procedure For these reasons ... all patients under-

going percutaneous vascular intervention should be observed in an acute care environment overnight" (cardiac catheterization guideline M), or "another criterion unique to transplantation in children is the demonstration of a reliable caregiver A pediatric transplant program has the obligation to seek a competent caregiver when one is not readily obvious" (heart transplant guideline D). Such guidelines describe psychosocial problems as indicators of need for extra intervention. This reasoning is guided less overtly by utilitarian concerns and is more in the spirit of an ethic of solidarity, 88,89 which holds that the community has some obligation to provide what individuals need. Social interventions (e.g., education, support groups), institutional arrangements or technology compensate for an otherwise adverse psychosocial characteristic: for example, "patient education prior to hospital discharge is important. It assists in achieving an acceptable quality-of-life for patients and their families, enables proper communication with the medical staff, and encourages patient compliance during the follow-up phase" (implantable defibrillator guideline O), and "many patients live far from a central pacemaker clinic and have difficulty attending regularly. For these patients, the most common means of follow-up is transtelephonic monitoring" (pacemaker guideline P).

Guidelines both describe and prescribe technology use. To the extent that guidelines merely describe practice, their content may give insights into the biases that already influence candidacy for cardiac procedures. By studying diverse guidelines that address many procedures and issue from various authors, we have described an approach to psychosocial issues that appears to transcend specific clinical problems and to represent a feature of academic medical culture.

As guidelines prescribe how procedures should be allocated better among potential candidates, they should be scrutinized not only for their validity as clinical tools, but also for their validity as distributive algorithms. In comparison with biomedical selection criteria, psychosocial selection criteria tend to be vaguely described and inadequately substantiated. Their uncritical, inconsistent or prejudicial application could unfairly limit access for vulnerable or marginal groups in society. Guidelines should advise readers of the source and quality of the evidence used^{2,92,93} and acknowledge contextual issues that bear on their recommendations. Frameworks for the development and critical appraisal of practice guidelines do not yet address these issues.

Discussions of psychosocial characteristics for patient selection in cardiac guidelines could be improved by 2 key reforms. First, guidelines could describe each psychosocial problem using clear and specific terminology and could suggest the most reliable and valid approach to assessing potential candidates. Second, guidelines could explain why particular psychosocial characteristics are important considerations, referring to a biological rationale, expert consensus or empirical evidence supporting the se-

lection criterion. Ideally, guidelines might note the possible distributive implications of following the criteria (even arguments based on outcome data are open to critique for their political and ethical implications). Disclosing the origins of and justifications for psychosocial contraindications might enhance their legitimacy and fairness, as ethicists advocate more open and publicly accessible rationales for rationing. 9,96,97

We used a multidisciplinary, qualitative approach to analyze recommendations regarding psychosocial selection criteria for cardiac procedures. We have interpreted and categorized the language used to discuss psychosocial issues and have identified some of the principles implied when patient selection criteria are reconceived as resource allocation criteria. Further studies are needed to understand the intentions of guideline developers and clinicians' interpretations of psychosocial selection criteria.

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Contributors: Dr. Giacomini was the principal investigator and guarantor. All the authors took part in data collection and analysis and the editing of the manuscript. Drs. Giacomini, Cook and Streiner were involved in the conception of the project and the writing of grant applications. Drs. Giacomini and Cook drafted the manuscript.

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