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Barriers and perceptions regarding code status discussion with families of critically ill patients in a tertiary care hospital of a developing country: A cross-sectional study

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1 Abstract

Background: In Asian societies including Pakistan, a complex background of illiteracy,
different familial dynamics, lack of patient's autonomy, religious beliefs and financial
constraints give new dimensions to code status discussion. Barriers faced by physicians
during code status discussion in these societies are largely unknown.

6 Aim: To determine the barriers and perceptions in discussion of code status by physicians.

7 **Design:** Questionnaire-based cross sectional study.

8 Setting and participants: This study was conducted in the Department of Medicine of
9 The Aga Khan University Hospital Karachi, Pakistan. 134 physicians who had discussed at
10 least five code statuses in their lifetime were included.

Results: A total of 77 (57.4%) physicians responded. Family-related barriers were found to be the most common barriers. They include family denial (74.0%), level of education of family (66.2%), and conflict between individual family members (66.2%). Regarding personal barriers, lack of knowledge regarding prognosis (44.1%), personal discomfort in discussing death (29.8%), and fear of legal consequences (28.5%) were the top most barriers. In hospital-related barriers, time constraint (57.1%), lack of hospital administration support (48.0%), and suboptimal nursing care after DNR (48.0%) were the

most frequent. There were significant differences among opinions of trainees when compared to those of attending physicians. Conclusion: Family-related barriers are the most frequent roadblocks in the end-of-life care discussions for physicians in Pakistan. Strengthening communication skills of physicians, and family education are the potential strategies to improve end-of-life care. Large multi-center studies are needed to better understand the barriers of code status discussion in developing countries. Keywords Do-Not-Resuscitate Orders, perceptions, physicians, Pakistan

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2 Key statements

3 What is already known about the topic?

- Physicians face barriers in code status discussion.
- Barriers faced by physicians in developing Asian countries are not known.

6 What this paper adds?

Family related barriers are the most significant barriers in code status discussion in
 developing Asian countries like Pakistan.

9 Implications for practice?

Training of physicians regarding their communication with families of critically ill
 patients, and education of families of terminally ill patients regarding end-of-life
 care can improve management of terminally ill patients.

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2 Introduction

3 Code status orders involve decisions about whether or not to conduct CPR 4 (cardiopulmonary resuscitation) in the event of cardiopulmonary arrest (1). During management of critically ill patients a time may come when aggressive efforts seem to be 5 futile and unduly prolong the dying process as majority of such patients have no hope for 6 7 prolong survival. Terminally ill patients who receive aggressive medical care, like CPR, experience significant morbidity and worse quality of life (2, 3). At this point the role of 8 9 treating physician emerges to discuss code status of the patient. However, discussing code 10 status is usually a difficult task for physicians (1-3). This difficulty is due to several well defined barriers in code status discussion including lack of communication skills, time 11 12 constraints, overestimation of values of therapies like CPR and mechanical ventilation, family reaction to discussion of death, family denial, and discomfort in discussing end-of-13 14 life issues (4-6). Early code status discussion leads to good quality of life and lower 15 distress in terminally ill patients (2, 7). Despite known beneficial effects of early code status discussion there is usually a delay in such discussion (2). 16

Cultural differences play an important role in determining ethical issues in medicine (8, 9). 1 2 Western healthcare systems emphasize patient autonomy (10). However, non-Western 3 cultures believe that families and not the individual patient should alone bear the effects of life threatening illness. This is the reason that in contrast to Western countries several 4 European and many Asian health care professionals and families, including those in 5 Pakistan, conceal serious diagnoses from the patient to protect them from emotional harm 6 7 of the disease. These cultures believe that open discussion of serious illness may provoke 8 anxiety and depression in terminally ill patients and they may lose hope (8). Moreover, Asian adults feel a responsibility to care for their aging parents. This sense of caring 9 obligates them to seek aggressive measures to prolong the lives of their aging patients even 10 11 when these aggressive measures do not seem to change the outcome (8).

Pakistan is a developing South Asian country and only about 2% of its gross domestic product is spent on healthcare (11). Due to illiteracy, poverty, insufficient resources, poor quality control, and cultural and religious beliefs Pakistani healthcare system is not competent enough to provide adequate healthcare services to the rapidly growing population (12). In Pakistan, code status is discussed with the family rather than the patient (13), which is a major difference between this society and other countries of the developed world. In Pakistan financial constraints also play a role when families decide about code status of their patients, which gives new dimensions to end-of-life care
discussion. Moreover, in a predominant Muslim society, like Pakistan, religious beliefs
also play very important role during do-not-resuscitation discussion (14). Somewhat
similar issues are faced by other Asian countries (9).

5 We have observed in our clinical practice that code status discussion is often delayed by 6 several physicians. This notion is also mentioned in the Western as well as Pakistani 7 studies (2, 5, 15, 16). Moreover, studies addressing this issue are very scarce in this part of 8 the world. Therefore, it is imperative to determine the roadblocks faced by physicians of 9 this part of the world during end-of-life discussions. Our objective was to determine the 10 perceptions and barriers in discussion of code status by physicians.

11

12 Methods

It was a cross sectional study conducted in the department of Medicine of The Aga Khan University Hospital Karachi, Pakistan. Ethical approval from the Ethical Review Committee of the institution was obtained (No. 2719-MED-ERC-13) before commencement of the study. It was conducted from September 2013 to February 2014. All physicians in the department of Medicine of The Aga Khan University Hospital who had

discussed at least five code statuses in their medical carrier were included in the study. The 1 included physicians comprised of residents, fellows and attending physicians. Residents 2 3 and fellows were post graduate trainees and did not have an exit exam certification. The attending physicians were those who had completed their postgraduate training and 4 possessed an exit exam certification e.g. Diplomate American Board, Member or Fellow of 5 Royal College of Physicians (MRCP or FRCP), or Fellow of College of Physician and 6 7 Surgeons Pakistan (FCPS). The attending physicians that did not have admitting privileges 8 were excluded from the study.

9 *Questionnaire development*

After extensive brainstorming and literature review a comprehensive questionnaire was 10 11 developed. Then the sections were developed and drafted by the principal investigator and 12 then reviewed by all co investigators. It included three sections in all: Section A comprised of questions on demographics like age, gender, post graduate qualification, designation, 13 name of section in which the physicians are working, duration of their current position, 14 15 duration since they were discussing code status, and approximate number of code status they discuss per three months. Section B included six items regarding perceptions related 16 17 to code status discussion. Each question in this section had four to six options. Section C

comprised of questions on barriers to physicians during code status discussion. It included
 29 items. There were subsections on personal, family and hospital related barriers (see
 Appendix 1). Each question (barrier) had a five point Likert scale: strongly agree, agree,
 neutral, disagree and strongly disagree. The questionnaire was pretested on five
 participants who were not included in the sample.

6 Data collection

A hospital wide email was circulated before the commencement of the study mentioning
details of the study. It served as an invitation to participate in the study. Questionnaires
were distributed to attending physicians individually and to trainees after academic
meetings. Residents filled the questionnaires in front of the data collector and discussion
among them was not allowed. Informed written consent was taken from each participant.
Each questionnaire required around 15 minutes to fill in. The forms were collected and
coded to maintain confidentiality.

14 *Data analysis*

15 For data analysis Statistical Package for Social Sciences SPSS version 19.0 (IBM Corp.

16 Released 2010. IBM SPSS Statistics for Windows, Version 19.0. Armonk, NY: IBM

1	Corp.) was used. Frequency and percentage for categorical variables, and mean (SD) for
2	quantitative variables were calculated. Chi square test was used to compare categorical
3	variables. P value of < 0.05 was considered as significant. For simplification in analysis,
4	responses in barriers were recoded. Strongly Agree and Agree were recoded as Agree.
5	Disagree, Strongly Disagree and Neutral were recoded as Disagree.

Results

Demographic information

We sent questionnaire to 134 physicians. Out of 134 physicians 77 (57%) physicians,
including 48 residents, two fellows and 27 attending physicians, responded to the
questionnaire. Out of these respondents 50 (65%) were male. Their mean age (SD) was
29.05 (15.8) years. Mean duration for which the participants were discussing code status
was 7.65 years and mean number of code status discussed was 21.46 per three months.
Physicians from internal medicine comprised the highest number with 27 (35%)
participants followed by pulmonology 15 (19%) and gastroenterology 12 (16%) (Table 1).

Perceptions about code discussion in physicians

A considerable number of 43 (55%) participants felt that code status should be discussed when patient gets sick, however, 23 (29%) felt that it should be discussed at first visit of patient irrespective of the severity of illness. Majority of the participants, 52 (67%), preferred counseling room for code status discussion as compared to corridor of ward by 21 (27%) or bedside by four (5%). Immediate family member was the preferred person to discuss code status for 63 (82%) participants. Majority 52 (67%) of them thought that code should be discussed by attending physicians rather than by senior residents 12 (16%).

8 Personal barriers in discussing code faced by physicians

Lack of knowledge regarding prognosis of a particular disease 34 (44%), personal 9 10 discomfort in discussing death 23 (30%), and fear of legal consequences 22 (28%) were the most frequent personal barriers for the participants in code status discussion. While 11 12 comparing trainees and attending physicians there was a significant difference among their opinions regarding personal discomfort in discussing death 20 (42%) vs three (10%) 13 (p=0.004), thought that code status discussion is the responsibility of primary physician 14 15 and not mine six (12%) vs 11 (38%) (p=0.009), and fear of legal consequences 18 (37%) vs four (13.8%) (p=0.026), respectively. Trainees considered personal discomfort in 16

discussing death and fear of legal consequences more as a barrier as compared to attending
 physicians (Table 2).

3 Hospital related barriers in discussing code faced by physicians

Time constraint 44 (57%), lack of hospital administration support in case of family 4 reaction 37 (48%) and poor nursing care after declaring DNR 37 (48%) were the most 5 frequent hospital related barriers in code status discussion. While comparing trainees and 6 7 attending physicians there was a significant difference among their opinions regarding hospital policies 24 (50%) vs three (10%) (p<0.001), lack of hospital administration 8 9 support in case of family reaction 29 (60%) vs eight (28%) (p=0.005), and time constraint 10 33 (69%) vs 11 (38%) (p=0.008), respectively. Trainees considered all these three more as 11 a barrier as compared to attending physicians (Table 3).

12 Family related barriers in discussing code faced by physicians

Family denial 57 (74%), level of education of family 51 (66%), and conflict between individual family members on decision of DNR 51 (66%) were the most frequent family related barriers in code status discussion. While comparing trainees and attending physicians there was a significant difference among their opinions regarding language

1	barrier of family 30 (62%) vs 10 (34%) (p =0.017), family thoughts that physician wants to
2	take off their hands from patient 26 (54%) vs eight (28%) (p =0.023), and patient or any
3	family member is a doctor 31 (65%) vs 11 (38%) (p =0.023), respectively. Trainees
4	considered all these three more as a barrier as compared to attending physicians (Table 4).

5 Out of 10 American-trained physicians eight (80%), and out of seven British-trained 6 physicians four (57%) wanted to discuss code status with family instead of the patient. 7 Except for the barriers namely lack of proper place for code status discussion in the 8 hospital (p=0.007), language barrier of family (p=0.035) and level of education of family 9 (p=0.036), there was no significant difference in the opinions of male and female 10 physicians.

11

12 **Discussion**

In this study we found that family related barriers played the most important role in discussing code status. Family denial, level of education of family, and conflict between individual family members on decision of DNR were the most frequent family related barriers. Regarding personal barriers, lack of knowledge regarding prognosis of a particular disease, personal discomfort in discussing death, and fear of legal consequences were the top most barriers. As far as hospital related barriers are concerned, time constraint, lack of hospital administration support in case of family reaction, and suboptimal nursing care after declaring DNR were the most frequent barriers. There were significant differences among opinions of attending physicians and trainee physicians in several barriers. However, male and female physicians have similar opinions in most of the barriers.

7 There are several reasons behind the emergence of family-related barriers as the most common barriers identified by our physicians. Firstly family has an important role to play 8 9 in code status discussion. Family becomes overwhelmingly involved in code discussion in this part of world because Pakistani society is relatively a family-centered society and an 10 11 individual is viewed primarily as a part of a family. When a patient, particularly an elder one, gets sick whole family is involved in decision making about health care of that 12 individual. Interestingly, majority of our American and British trained physicians wanted 13 14 to discuss code with the family rather than patient. This is in contrast to their training done in Western societies where patient's autonomy is given prime importance. This indicates 15 16 that code status discussion is dependent more on socio-cultural background of patients 17 rather than academic background of physicians.

Secondly, in this society patients are often not informed about their terminal illness to 1 protect them from anxiety and depression (8-10). This leads to decision making, regarding 2 3 end-of-life care, by several individual family members rather than the patient himself. Thus decision making becomes a complex task due to conflict between individual family 4 members. Similar family behavior has also been observed in other societies like Japan, 5 many African countries, Spain, Bosnia, and Italy as showed by Searight et al in their study 6 7 (8). A study from Hong Kong with a predominant Chinese population, showed similar family-related issues in code status discussion including decisions regarding end-of-life 8 9 care and withdrawal of support being made by family members rather than the patient, and protecting patient from disclosure of grave prognosis of a disease. (9). A study by Anselm 10 11 et al, in which nurses and physicians were interviewed, reflects similar family related barriers in Canadian society including shielding of patients from these discussions, 12 difficulty in assigning a decision maker, impact of different cultural and religious values, 13 14 and understanding capacity of family members (6). Siddiqui and colleagues interviewed internal medicine residents of an American university. Around half of the participants 15 16 mentioned lack of patient's or family's understanding as the major impediment to DNR 17 discussion (17). Although cultural values of the American and Canadian societies are significantly different from those of Pakistani society, still family related factors play an
 important role in code status discussion.

3

Thirdly, family denial is an important cause of delay in code status discussion and has also 4 been observed by Baig in this part of world (18). Due to relatively low literacy rate, family 5 6 members of Pakistani patients have overestimation of therapies like CPR and mechanical 7 ventilation. Moreover, being a Muslim predominant society many families believe in a divinely predestined time of death which is not under control of human beings. Thus 8 discussion regarding the duration of remaining life seems to be meaningless for many 9 10 families (10). This leads to family denial where family avoids any steps which hasten the 11 death of their patient. Nedjat-Haiem in her study conducted interviews of healthcare providers who were providing care to patients who belonged to low-income stratum. 12 Among other family related barriers, she found denial of families and their fight to keep 13 14 patient alive as important barriers (7). Denial was also found to be a barrier by Anselm (6).

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16 Since, family related barriers emerged as the most common barriers faced by physicians in 17 this part of the world, our recommendation would focus on strengthening the 18 communication skills of physicians particularly focusing communication with such families. Education of families of terminally ill patients, e.g. by developing information brochures in local languages, including information regarding CPR, mechanical ventilation and management of terminally ill patients, may have a significant impact on improvement of code status discussions. Counseling sessions of such families by trained nurses may be another strategy. Moreover, Searight suggested that physicians should elicit the cultural norms of their patients, particularly family related issues, before starting code status discussion (8).

8

9 Among the hospital related barriers, time constraint was the most common barrier 10 identified by our physicians. It is not unusual in a busy tertiary care hospital, like ours, to 11 have time constraint as the most frequent barrier faced by physicians due to several competing demands including progressively increasing number of patients admitted to the 12 hospital with majority being elderly and critically sick, maintaining a balance between 13 14 clinical service, research and teaching requirements, and burden of outpatient clinics. Time constraint has also been reported in other studies as an important barrier in code status 15 discussion (5, 7, 17, 19, 20). In this regard the recommendation by Eliasson (5) to 16 17 reimburse the time spent by a physician for code status discussion seems much reasonable. 18 Lack of hospital administration support in case of a family reaction and suboptimal nursing

care after declaring DNR have emerged as other hospital related barriers. Hafeez et al also mentioned that suboptimal care after declaring DNR is a barrier in discussing code status in this part of the world. Physicians feel that if patients are declared DNR then they will not get adequate care and attention (13). Regarding family reactions, policies are in place, however, in case of deterioration or death of a patient the situation gets complex. This fact suggests that proper and graded counseling of patients at appropriate time is very important.

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9 Lack of knowledge regarding prognosis of a particular disease is the most common 10 personal barrier identified by our physicians. Rhodes (20) and Morrison (19) also 11 identified lack of knowledge of physicians as a barrier. Without having knowledge of prognosis of a disease, end-of-life care discussion is not only difficult but may be 12 unethical. However, it is impossible for a physician to be knowledgeable about the 13 14 prognosis of every disease. To overcome this issue, it might be beneficial that primary physician should discuss code status with family in the presence of a physician who is 15 16 expert in that particular disease.

The strength of our study is that it is the first study of its kind in a developing South Asian 1 country. However, our study has some limitations as well. This study focused on a small 2 3 sample size from a single tertiary care institution which may limit its generalization. There is a need for similar research in other developing Asian countries to know the barriers 4 faced by their physicians. Secondly, since this was a questionnaire based study, the 5 possibility of recall bias could not be ruled out. Thirdly, the level of trainees in this study 6 7 was variable, junior residents being more than senior residents which might have 8 overestimated the results. Moreover, we have recoded the Likert scale of our questionnaire 9 which can have confounding effects on the results.

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11 Conclusion

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Physicians in this part of the world face family related barriers as the most frequent roadblocks in end-of-life care discussions. Strengthening communication skills of physicians particularly focusing communication with families, and family education are the potential strategies to improve end-of- life care of terminally ill patients. Large multicenter studies are required to better understand the barriers of code status discussion in developing Asian countries.

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commercial, or not-for-profit sectors.
Declaration of conflicting interest
We declare that we have no conflict of interest.
Data:
Due to our institutional policies we cannot dis
special circumstances we can ask our Ethical Re
Table 1. Baseline characteristics of participants.
Baseline characteristics
Male
Mean age (years \pm SD)

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ring questionnaire development. 3

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- sclose the data of our study. However, in 10

n (%)

50 (64.9)

 29.05 ± 15.80

 7.65 ± 7.20

- eview Committee for sharing of data. 11
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Mean duration of code status discussion (years

± SD)	
Mean number of code status discussed per three months ($n \pm SD$)	21.46 ± 31.44
Specialty	
Internal Medicine	27 (35.06)
Neurology	9 (11.7)
Pulmonology/Critical care	15 (19.48)
Cardiology	11 (14.3)
Gastroenterology	12 (15.6)
Nephrology	3 (3.9)
Qualification	
FCPS	16 (20.8)
Diplomat American board	10 (12.9)
MRCP	4 (5.2)
FRCP	3 (3.9)
Designation	
Resident	48 (62.0)
Fellow	2 (2.6)
Attending physician	27 (35.1)

- college of physicians; FRCP: fellow of royal college of physicians.

5	Table 2. Personal	barriers in	physicians	regarding	code discussion.
5		ourrens m	physicians	reguianns	couc anocassion.

Barriers	Overall n (%) n=77	Trainees <i>n</i> (%) <i>n</i> =50	Attendings n (%) n=27	<i>p</i> value ^a
Personal discomfort in discussing death	23 (29.9)	20 (41.7)	3 (10.3)	0.004
Fear that raising the topic of death will compromise the doctor–patient relationship	13 (16.9)	10 (20.8)	3 (10.3)	0.234
Code status discussion is responsibility of primary physician and not mine	17 (22.1)	6 (12.5)	11 (37.9)	0.009
Lack of knowledge regarding prognosis of a particular disease	34 (44.2)	22 (45.8)	12 (41.4)	0.703
Fear of legal consequences	22 (28.6)	18 (37.5)	4 (13.8)	0.026
Lack of my training in communication skills (specially code status discussion)	8 (10.4)	7 (14.6)	1 (12.5)	0.121
I think I am a symbol of hope and not death $6 {}^{a}p$ value is between attending physicians a	15(19.5)	12 (25.0)	3 (10.3)	0.116

Barriers	Overall	Trainees	Attendings	p value ^a
	n (%)	n (%)	n (%)	
	<i>n</i> =77	<i>n</i> =50	<i>n</i> =27	
Time constraint	44 (57.1)	33 (68.8)	11 (37.9)	0.008
Hospital policies	27 (35.1)	24 (50.0)	3 (10.3)	0.000
Lack of proper place/room for such discussion in our hospital	35 (45.5)	24 (50.0)	11 (37.9)	0.303
Lack of hospital administration support in case of family reaction	37 (48.1)	29 (60.4)	8 (27.6)	0.005
Poor care by doctors after declaring DNR	29 (37.7)	20 (41.7)	9 (31.0)	0.351
Poor nursing care after declaring DNR	37 (48.1)	27 (56.3)	10 (34.5)	0.064

2 **Table 3.** Hospital related barriers in physicians regarding discussing code discussion.

3 ^ap value is between attending physicians and trainees

25 (32.5)

17 (35.4)

8 (27.6)

0.477

Lack of trained nurses

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9	Table 4. Family related barriers in discussing code faced by physicians.
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Barriers	Overall	Trainees	Attendings	<i>p</i> value ^a
	n (%)	n (%)	n (%)	
	<i>n</i> =77	<i>n</i> =50	<i>n</i> =27	
Code status should be discussed with patient and not with family	32 (41.6)	23 (47.9)	9 (31.0)	0.145
Discussing code status will take away their hope	11 (14.3)	9 (18.8)	2 (6.9)	0.150
Fear of family reaction	21 (27.3)	17 (35.4)	4 (13.8)	0.039
Family may think that the physician wants to take off their hands from patient	34 (44.2)	26 (54.2)	8 (27.6)	0.023
Family denial	57 (74.0)	37 (77.1)	20 (69.0)	0.431
Family leaves decision on physician	39 (50.6)	24 (50.0)	15 (51.7)	0.883
Families do not take recommendation by physicians	22 (28.6)	15 (31.3)	7 (24.1)	0.503
Conflict between individual family members on decision of DNR	51 (66.2)	34 (70.8)	17 (58.6)	0.272
Patient or any family member is doctor	42 (54.5)	31 (64.6)	11 (37.9)	0.023
Language barrier of family	40 (51.9)	30 (62.5)	10 (34.5)	0.017
Secondary gains by family members (e.g. issues related to inheritance)	24 (31.2)	18 (37.5)	6 (20.7)	0.123

Level of education of fam	nily 51 (66.2)) 36 (75.0)	15 (51.7)	0.036
1 ^a <i>p</i> value is between attending physicians and trainees				
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