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1 *Original Article*

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

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1 **Abstract**

2 **Background:** In Asian societies including Pakistan, a complex background of illiteracy,
3 different familial dynamics, lack of patient's autonomy, religious beliefs and financial
4 constraints give new dimensions to code status discussion. Barriers faced by physicians
5 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.

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

1 most frequent. There were significant differences among opinions of trainees when
2 compared to those of attending physicians.

3 **Conclusion:** Family-related barriers are the most frequent roadblocks in the end-of-life
4 care discussions for physicians in Pakistan. Strengthening communication skills of
5 physicians, and family education are the potential strategies to improve end-of-life care.
6 Large multi-center studies are needed to better understand the barriers of code status
7 discussion in developing countries.

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9 **Keywords**

10 Do-Not-Resuscitate Orders, perceptions, physicians, Pakistan

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2 Key statements**3 What is already known about the topic?**

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

6 What this paper adds?

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

9 Implications for practice?

- 10 • Training of physicians regarding their communication with families of critically ill
11 patients, and education of families of terminally ill patients regarding end-of-life
12 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
5 management of critically ill patients a time may come when aggressive efforts seem to be
6 futile and unduly prolong the dying process as majority of such patients have no hope for
7 prolong survival. Terminally ill patients who receive aggressive medical care, like CPR,
8 experience significant morbidity and worse quality of life (2, 3). At this point the role of
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
11 defined barriers in code status discussion including lack of communication skills, time
12 constraints, overestimation of values of therapies like CPR and mechanical ventilation,
13 family reaction to discussion of death, family denial, and discomfort in discussing end-of-
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
16 status discussion there is usually a delay in such discussion (2).

1 Cultural differences play an important role in determining ethical issues in medicine (8, 9).
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
4 life threatening illness. This is the reason that in contrast to Western countries several
5 European and many Asian health care professionals and families, including those in
6 Pakistan, conceal serious diagnoses from the patient to protect them from emotional harm
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,
9 Asian adults feel a responsibility to care for their aging parents. This sense of caring
10 obligates them to seek aggressive measures to prolong the lives of their aging patients even
11 when these aggressive measures do not seem to change the outcome (8).

12 Pakistan is a developing South Asian country and only about 2% of its gross domestic
13 product is spent on healthcare (11). Due to illiteracy, poverty, insufficient resources, poor
14 quality control, and cultural and religious beliefs Pakistani healthcare system is not
15 competent enough to provide adequate healthcare services to the rapidly growing
16 population (12). In Pakistan, code status is discussed with the family rather than the
17 patient (13), which is a major difference between this society and other countries of the
18 developed world. In Pakistan financial constraints also play a role when families decide

1 about code status of their patients, which gives new dimensions to end-of-life care
2 discussion. Moreover, in a predominant Muslim society, like Pakistan, religious beliefs
3 also play very important role during do-not-resuscitation discussion (14). Somewhat
4 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**

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

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

9 *Questionnaire development*

10 After extensive brainstorming and literature review a comprehensive questionnaire was
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
13 of questions on demographics like age, gender, post graduate qualification, designation,
14 name of section in which the physicians are working, duration of their current position,
15 duration since they were discussing code status, and approximate number of code status
16 they discuss per three months. Section B included six items regarding perceptions related
17 to code status discussion. Each question in this section had four to six options. Section C

1 comprised of questions on barriers to physicians during code status discussion. It included
2 29 items. There were subsections on personal, family and hospital related barriers (see
3 Appendix 1). Each question (barrier) had a five point Likert scale: strongly agree, agree,
4 neutral, disagree and strongly disagree. The questionnaire was pretested on five
5 participants who were not included in the sample.

6 *Data collection*

7 A hospital wide email was circulated before the commencement of the study mentioning
8 details of the study. It served as an invitation to participate in the study. Questionnaires
9 were distributed to attending physicians individually and to trainees after academic
10 meetings. Residents filled the questionnaires in front of the data collector and discussion
11 among them was not allowed. Informed written consent was taken from each participant.
12 Each questionnaire required around 15 minutes to fill in. The forms were collected and
13 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.

6

7 **Results**

8 *Demographic information*

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

16 *Perceptions about code discussion in physicians*

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

8 *Personal barriers in discussing code faced by physicians*

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

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

3 *Hospital related barriers in discussing code faced by physicians*

4 Time constraint 44 (57%), lack of hospital administration support in case of family
5 reaction 37 (48%) and poor nursing care after declaring DNR 37 (48%) were the most
6 frequent hospital related barriers in code status discussion. While comparing trainees and
7 attending physicians there was a significant difference among their opinions regarding
8 hospital policies 24 (50%) vs three (10%) ($p<0.001$), lack of hospital administration
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*

13 Family denial 57 (74%), level of education of family 51 (66%), and conflict between
14 individual family members on decision of DNR 51 (66%) were the most frequent family
15 related barriers in code status discussion. While comparing trainees and attending
16 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**

13 In this study we found that family related barriers played the most important role in
14 discussing code status. Family denial, level of education of family, and conflict between
15 individual family members on decision of DNR were the most frequent family related
16 barriers. Regarding personal barriers, lack of knowledge regarding prognosis of a
17 particular disease, personal discomfort in discussing death, and fear of legal consequences

1 were the top most barriers. As far as hospital related barriers are concerned, time
2 constraint, lack of hospital administration support in case of family reaction, and
3 suboptimal nursing care after declaring DNR were the most frequent barriers. There were
4 significant differences among opinions of attending physicians and trainee physicians in
5 several barriers. However, male and female physicians have similar opinions in most of the
6 barriers.

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

18

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

1 significantly different from those of Pakistani society, still family related factors play an
2 important role in code status discussion.

3

4 Thirdly, family denial is an important cause of delay in code status discussion and has also
5 been observed by Baig in this part of world (18). Due to relatively low literacy rate, family
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
8 divinely predestined time of death which is not under control of human beings. Thus
9 discussion regarding the duration of remaining life seems to be meaningless for many
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
12 providers who were providing care to patients who belonged to low-income stratum.
13 Among other family related barriers, she found denial of families and their fight to keep
14 patient alive as important barriers (7). Denial was also found to be a barrier by Anselm (6).

15

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

1 families. Education of families of terminally ill patients, e.g. by developing information
2 brochures in local languages, including information regarding CPR, mechanical ventilation
3 and management of terminally ill patients, may have a significant impact on improvement
4 of code status discussions. Counseling sessions of such families by trained nurses may be
5 another strategy. Moreover, Searight suggested that physicians should elicit the cultural
6 norms of their patients, particularly family related issues, before starting code status
7 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
12 competing demands including progressively increasing number of patients admitted to the
13 hospital with majority being elderly and critically sick, maintaining a balance between
14 clinical service, research and teaching requirements, and burden of outpatient clinics. Time
15 constraint has also been reported in other studies as an important barrier in code status
16 discussion (5, 7, 17, 19, 20) . In this regard the recommendation by Eliasson (5) to
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

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

8

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
12 prognosis of a disease, end-of-life care discussion is not only difficult but may be
13 unethical. However, it is impossible for a physician to be knowledgeable about the
14 prognosis of every disease. To overcome this issue, it might be beneficial that primary
15 physician should discuss code status with family in the presence of a physician who is
16 expert in that particular disease.

17

1 The strength of our study is that it is the first study of its kind in a developing South Asian
2 country. However, our study has some limitations as well. This study focused on a small
3 sample size from a single tertiary care institution which may limit its generalization. There
4 is a need for similar research in other developing Asian countries to know the barriers
5 faced by their physicians. Secondly, since this was a questionnaire based study, the
6 possibility of recall bias could not be ruled out. Thirdly, the level of trainees in this study
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.

10

11 **Conclusion**

12

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

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2 **Acknowledgements**

3 We acknowledge the help of Dr Junaid Patel during questionnaire development.

4 **Funding**5 This research received no specific grant from any funding agency in the public,
6 commercial, or not-for-profit sectors.7 **Declaration of conflicting interest**

8 We declare that we have no conflict of interest.

9 **Data:**10 Due to our institutional policies we cannot disclose the data of our study. However, in
11 special circumstances we can ask our Ethical Review Committee for sharing of data.

12

13

14 **Table 1.** Baseline characteristics of participants.

Baseline characteristics	<i>n</i> (%)
Male	50 (64.9)
Mean age (years \pm SD)	29.05 \pm 15.80
Mean duration of code status discussion (years	7.65 \pm 7.20

± SD)	
Mean number of code status discussed per three months (<i>n</i> ± 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)

1 FCPS: fellow of college of physicians and surgeons (Pakistan); MRCP: member of royal
 2 college of physicians; FRCP: fellow of royal college of physicians.

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5 **Table 2.** Personal barriers in physicians regarding code discussion.

Barriers	Overall <i>n</i> (%) <i>n</i> =77	Trainees <i>n</i> (%) <i>n</i> =50	Attendings <i>n</i> (%) <i>n</i> =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	15 (19.5)	12 (25.0)	3 (10.3)	0.116

6 ^a*p* value is between attending physicians and trainees

7

1

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

Barriers	Overall <i>n</i> (%) <i>n</i> =77	Trainees <i>n</i> (%) <i>n</i> =50	Attendings <i>n</i> (%) <i>n</i> =27	<i>p</i> value ^a
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
Lack of trained nurses	25 (32.5)	17 (35.4)	8 (27.6)	0.477

3 ^a*p* value is between attending physicians and trainees

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Table 4. Family related barriers in discussing code faced by physicians.

Barriers	Overall <i>n</i> (%) <i>n</i> =77	Trainees <i>n</i> (%) <i>n</i> =50	Attendings <i>n</i> (%) <i>n</i> =27	<i>p</i> value ^a
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 family	51 (66.2)	36 (75.0)	15 (51.7)	0.036
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1 ^a*p* value is between attending physicians and trainees

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