A Comparison of Attitudes of Physicians and Patients Regarding Communication and Decision-making in End-of-life issues and Cardiopulmonary Resuscitation at the University Hospital of the West Indies, Mona, Jamaica

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ABSTRACT

Background: There is evidence suggesting that the discussions regarding cardiopulmonary resuscitation (CPR) and other end-of-life (EOL) issues are difficult for both physicians and patients and occur less frequently than is desirable. This may result in management decisions being inadvertently at variance between physicians and patients.

Aim: To determine the attitudes of physicians and patients attending outpatient clinics towards CPR and EOL issues at the University Hospital of the West Indies (UHWI), Jamaica.

Methods: This was an observational, questionnaire-based study. An 18-item self-administered questionnaire was used to assess physicians' attitudes and a separate 21-item questionnaire was administered to clinic attendees from the medical and surgical subspecialities.

Results: Most of the physicians (95%) and patients (89%) believed in a patient's right to choose or refuse CPR. Both groups supported shared decision-making, though the patients wanted this only if they are incapacitated. The physicians were not regularly initiating discussions with patients about CPR and EOL issues, with 37% of them indicating that they conducted these discussions only "sometimes" and 20% never had these discussions. The physicians' lack of confidence in their communication skills may be contributory; only 50% of them felt that their skills were "frequently" or "always" adequate. The patients expressed their willingness to have discussions with their physicians (73%), but many preferred to have these discussions only in the event of complications (56%).

Conclusion: The study suggests that communication about resuscitation between physicians and patients in our institution is suboptimal and improvement is needed. Formal training in communicating difficult issues should be introduced in undergraduate and postgraduate courses and reinforced during an ongoing continuing medical education.

Keywords: Cardiopulmonary resuscitation, communication, end-of-life issues, patients' attitudes, physicians' attitudes

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Comparación de las Actitudes de los Médicos y de los Pacientes con Respecto a la Comunicación y la Toma de Decisiones en Cuestiones Relacionadas con el in de la Vida y Resucitación Cardiopulmonar en el Hospital Universitario de West Indies, Mona, Jamaica

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RESUMEN

Antecedentes: Las evidencias sugieren que las discusiones con respecto a la resucitación cardiopulmonar (RCP) y otras cuestiones relacionadas con el fin de la vida (FDV) son difíciles tanto para los médicos como para los pacientes, y ocurren con menos frecuencia de lo que es deseable. Esto puede dar lugar a decisiones de manejo inadvertidamente divergentes entre médicos y pacientes.

Objetivo: Determinar las actitudes de los médicos y pacientes que asisten a las clínicas ambulatorias hacia los temas de RCP y FDV en el Hospital Universitario de West Indies (HUWI), Jamaica.

Métodos: Se trató de un estudio observacional, basado en cuestionarios. Se utilizó un cuestionario autoadministrado de 18 ítems para evaluar las actitudes de los médicos, y se administró un cuestionario separado de 21 ítems a los asistentes a la clínica de las subespecialidades médicas y quirúrgicas.

Resultados: La mayoría de los médicos (95%) y los pacientes (89%) creían en el derecho de un paciente a elegir o rechazar la RCP. Ambos grupos apoyaron la toma de decisiones compartida, aunque los pacientes querían esto sólo en el caso de hallarse incapacitados. Los médicos no estaban iniciando regularmente discusiones con los pacientes sobre RCP y los asuntos de FDV, 37% de ellos indicando que realizaban estas discusiones solamente "a veces", y 20% informando que nunca tenían estas discusiones. La falta de confianza de los médicos en sus habilidades comunicativas puede ser un factor que contribuye a ello; sólo el 50% de ellos sentían que sus habilidades eran "frecuentemente" o "siempre" adecuadas. Los pacientes expresaron su voluntad de tener discusiones con sus médicos (73%), pero muchos prefirieron tener estas discusiones solamente en caso de complicaciones (56%).

Conclusión: El estudio sugiere que la comunicación que en torno a la resucitación sostienen médicos y pacientes en nuestra institución, está lejos de ser óptima y necesita mejorar. El entrenamiento formal para comunicar asuntos difíciles debe ser introducido en los cursos de pregrado y posgrado, y reforzado luego durante la educación médica continua.

Palabras clave: Resucitación cardiopulmonar, comunicación, cuestiones del final de la vida, actitudes de los pacientes, actitudes de los médicos

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INTRODUCTION

The ethical principle of patients' autonomy highlights patients' rights to make informed decisions regarding their own medical treatment (1). However, studies have shown that conversations between physicians and their patients about the patients' preferences for terminal care, including; cardiopulmonary resuscitation (CPR), occur infrequently (2). In one study of 200 medical in-patients,

only 16% of the patients reported having discussed life support with their physicians, while an additional 47% desired such discussions (3). Kerridge *et al* reported that only 29% of patients had discussed CPR with their doctors or their families, though 80% believed they should be involved in CPR decisions (4). Physicians and families are often unaware of patients' preferences for life sustaining therapies and there is poor agreement between

what a physician or family member thinks that a patient would want and the patient's expressed preferences (5, 6). This lack of communication may result in avoidable unwanted or unintended adverse outcomes and an unnecessary increased use of hospital resources (7).

In recognition of this problem, many authorities have suggested having discussions to establish patients' goals for end-of-life (EOL) issues (3, 4, 7-11). End-of-life issues are those concerning the care and management of patients whose condition or illness will likely end in death and for which there is no treatment that can substantially alter the outcomes (12). These include: decisions regarding institution of resuscitative or life sustaining measures and dealing with debilitating pain (12). Thus, the idea of advanced care planning (ACP) was born, which is the process by which patients in conjunction with their physicians and family, establish the goals and preferences for the patients' future care (9). Written documentation of a patient's and/or family members' desires regarding EOL issues include "do not resuscitate" (DNR) orders and living wills and are known as advanced directives (9). Although ACP and the use of advanced directives are recognized legally in the United States of America (USA) and other first world countries (13, 14), they have not gained widespread acceptance in the Englishspeaking Caribbean and remain a grey area legally.

This study sought to determine the attitudes of physicians and clinic attendees from a teaching hospital in Kingston, Jamaica, to CPR and EOL issues and to evaluate the dynamics of the doctor-patient communications regarding these issues.

SUBJECTS AND METHOD

A single-centre, cross-sectional study was conducted at the University Hospital of the West Indies (UHWI), Kingston, Jamaica. This is a 453-bed urban teaching hospital affiliated to The University of the West Indies. It is the tertiary referral centre for the Island with two of the only five intensive care units in the country and manages a population of patients in whom EOL issues are most pertinent. A self-administered questionnaire was used to interview physicians from internal medicine, surgery, emergency medicine, anaesthesia and intensive care, obstetrics and gynaecology at all levels of qualification, from the interns (house officers) to the consultant. The surveys took place over a ten-month period from March 2010 to January 2011 and 220 physicians were targeted based on the monthly departmental schedules. The physicians were given 18 questions covering the demographic data, attitude and communication with

regards to CPR and EOL issues. The questions designed to assess their attitude were based on a five-point Likert Scale (always to never).

A second questionnaire was used to survey the patients who were attendees at the following outpatient clinics: general surgery, internal medicine, haematology (oncology) and gynaecology. The eligible patients were interviewed privately, by one of three trained research assistants using a standard data collection sheet. Eligibility was determined as clinic attendees willing to participate, between 17 and 85 years old and who were English-speaking. Each patient was administered a 21-item questionnaire which included their demographic data as well as questions designed to assess their attitude to CPR, desire for information and level of doctor-patient communication. A sample size of 205 was calculated based on an expected frequency of 80% from a similar study which reviewed decision-making in cardiopulmonary resuscitation (4) and to obtain a power of 95% and confidence interval of five per cent.

The data collected from both questionnaires were analysed using the SPSS v 16.0 statistical programme. The results generated were assessed using unpaired t-test or Chi-square methods and p-values < 0.05 were considered statistically significant. The study was approved by The University of the West Indies, Faculty of Medical Sciences, Mona, Ethics committee.

RESULTS

Physicians demographics

Of the 220 physicians targeted, 154 responded and 143 had correctly completed the questionnaire; this constituted to a valid response rate of 65%. There were 77 (55%) females and the majority of respondents were between 26 and 30 years of age [41%] (Fig. 1). There were only eight (5.6%) physicians over 40 years of age. Most of the respondents were surgeons (41%), followed by anaesthetists (18%), internists (15%), emergency physicians (11%), obstetricians and gynaecologists (10%) and oncologists (5%). The residents accounted for 62% of the respondents, house officers 24% and consultants 14%.

Physician attitudes

Most of the physicians (95%) believed that patients had the right to choose or refuse CPR. However, many felt that the patients should make any advanced decisions regarding CPR in conjunction with their family and the physicians (70%) and 21% expressed the opinion that

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these decisions were best made by only the family and the physicians. They further indicated that patients' wishes (71.4%), quality of life considerations (38.1%) and patients' diagnoses (30.6%) were the most important factors they considered when making decisions about CPR. The other factors, such as the mental state of the patients (16.4%) and family wishes (14.8%) were not considered as important.

Physician communication

Most of the respondents were engaging in discussions about their patients' desires regarding CPR only "sometimes" [37%] (Fig 2). Additionally, 20% of the physicians indicated that they never discussed their patients' desires for resuscitation. Only 10% of the doctors said they had these discussions "most times" and 4% "always" had these discussions with their patients. Approximately, nine per cent of the physicians reported that they would have these discussions with patients only if asked directly. Most of the physicians believed that the ideal timing for EOL discussions should be when the

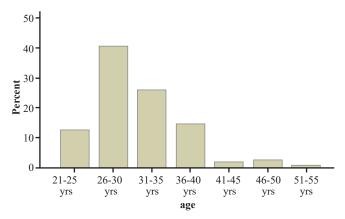


Fig. 1: Distribution of physician-respondents according to age.

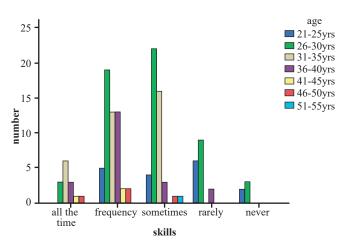


Fig. 3: Physician perception of their communication skills against age.

patient is critically ill (72%) or if death was imminent (16%). Only four per cent of the physicians would routinely have these discussions on patients' admission to the hospital. The specialties that had undertaken most discussions were internal medicine (90%), surgery and haematology/oncology (71% each). Anaesthesia (58%) and accident and emergency (43%) had the least discussions (p = 0.066).

Approximately, half of the physicians thought that their communication skills with respect to CPR and EOL issues were "frequently" adequate (40%) or "all the time" (10%). The remainder chose "sometimes" (35%), "rarely" (12%) and "never" four per cent. The younger and more junior physicians thought that their skills were less adequate than the older and more senior colleagues [p = 0.031 and p = 0.001, respectively] (Fig 3)

Approximately 41% of the physicians felt that their patients were frequently satisfied with their CPR/ EOL discussions, 33% felt that their patients were satisfied sometimes and 15% felt that their patients were satisfied all the time (Fig. 4).

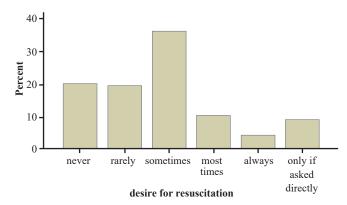


Fig. 2: Physician responses to having discussions with patients on desires for resuscitation.

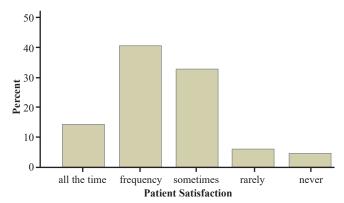


Fig. 4: Physician perception of patient satisfaction with respect to how they communicate with them about cardiopulmonary resuscitation and end-of-life issues.

Patient demographics

Two hundred and five patients were evaluated, the majority (39%) being from the haematology /oncology clinics. There was a female predominance (73%). The age distribution is shown in (Fig. 5).

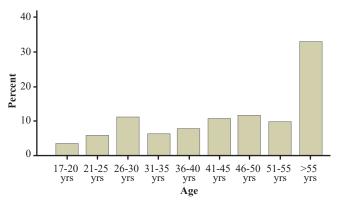


Fig. 5: Distribution of patient respondents by age.

Most were married or in common law relationships (51%) and had up to a secondary school education level (73%). The patients were asked to rate their present state of health and 29% thought that their health was excellent. The majority, 63% chose good or fair while four per cent thought that their health was poor.

Patient attitudes

Most of the patients believed that their opinion was paramount when making life and death decisions about their care (89.4%) [Table. 1]. Most of the patients (79%) indicated that they would choose the physician along with their family to be the decision-makers if they became incapacitated. Of those patients who wanted to have dis-cussions, most indicated their health to be good (73%). Conversely, of those who did not want to have discussions, approximately 45% deemed their health to be fair or poor.

Patients' opinions on communication

Most of the patients indicated a willingness to have discussions with their doctors about their care (73%), but wanted to have these discussions only if there was a complication or a problem (56%) [Table. 1].

The majority of the patients did not think that the talk of resuscitation was cruel or insensitive (91%). However, only 37% of the patients always found it easy to have these discussions with their doctors. Most (46%), of them indicated this was "sometimes" easy and four per cent found that these discussions were infrequent or never easy to engage in.

Living wills

Only 16% of the physicians indicated that they had a living will. Approximately 40% of those who had a living will were between the ages of 26 and 30 years (Fig. 6). There was no difference in the frequency of living wills between younger and older physicians (p = 0.1).

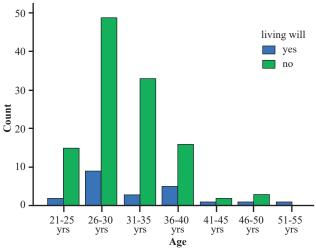


Fig. 6: Physician responses to having a living will by age.

DISCUSSION

End-of-life issues are a sensitive area and particularly subject to cultural influences. This paper examined these in a developing, resource poor country and from the perspective of both the physicians and the patients. The population surveyed appeared to be in a transition phase, from a reliance on the physician for major decisions towards patients becoming active participants in their medical care.

Table 1: Patient responses on desires for their care

| Question | Frequency (%) |
|---|---------------|
| Would you like to have discussions with your doctor? | |
| Yes | 141 (73.1) |
| No | 49 (25.4) |
| When would you like these discussions to occur? | |
| On admission | 50 (32.7) |
| Only if a complication | 85 (55.6) |
| Should patients make their own decisions regarding life and death issues? | |
| Yes | 177 (89.4) |
| No | 3 (1.5) |
| Unsure | 18 (9.1) |
| Do you want to be involved in making life and death decisions? | |
| Yes | 182 (91.9) |
| No | 4.0 (2.0) |

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Our findings indicated that the overwhelming majority of both patients and physicians agreed with the principle of patient autonomy regarding decisions about EOL issues, a position reflected in research from other Regions (4, 15–18). In addition, both groups accepted that shared decision-making was an important part of the process, with the physician as the facilitators and involving their family if they became incapacitated. These findings are similar to the studies in other countries (4, 7, 11). The physicians indicated that the patients' wishes, quality of life and diagnoses as the most important factors in making decisions about CPR for their patients. These factors were also considered most important by about two-thirds of all the respondents in a study of over 500 healthcare professionals and 150 patients from a teaching hospital in Australia (4).

Our findings suggest that, in general, most of the patients (73%) desired discussion on EOL issues. In a literature review by Layson *et al*, 53–87% of patients wished to discuss their preferences for life support with their doctors (19). But contradictions exist; a study examining EOL preferences in elderly patients revealed that 95% of the patients wanted to discuss EOL issues with their physicians (11), a finding supported by our data. However, Deber *et al* demonstrated that older patients were less likely to want information (20).

Also of note, and contrary to our expectations, the patients in this study, who considered their health to be poor, were less likely to desire discussions on EOL issues. This may be attributed to patients in poor health not wanting to face their own mortality. In one study, patients in poor health described wanting to concentrate on staying alive rather, than talking about death (7). The patients in our study also only wanted EOL discussions in the event of a complication which suggests that they do not want it to be a routine part of admission, but only if, in their opinion, the situation warrants it. The optimal timing of EOL discussion apparently will vary on a cultural basis and individually within a given culture and as such it may serve the interests of all concerned for us to train our doctors to enquire about what would be the appropriate time to broach the subject of death and dying.

In spite of the high number of patients who expressed a desire for more information, our findings suggested that only 14% of the physicians at the University Hospital of the West Indies were having these discussions regularly. This discrepancy might be due to the finding that although a high number of patients indicated an interest in EOL discussion, the majority did not want to have the conversation unless there was a perceived risk of death.

Such contradictions make the decision on whether or not to discuss EOL issues more difficult for the doctor. Evidence suggests that such discussions are generally difficult for the physicians. A study, which assessed the attitudes of junior doctors who had participated in CPR as a part of cardiac arrest teams at a district general hospital in the United Kingdom, revealed that 58% of the junior doctors found it difficult to discuss CPR with the patients and 46% of them found it difficult to discuss CPR with their relatives (1). One study identified time constraints and not yet developing a relationship with the patients as obstacles to EOL discussions (9). These may also apply in our population. Though physicians perceived discussions about CPR as being too stressful for patients, this is not supported by the patients' responses in this study and the wider literature. It has been noted that most patients do not find these discussions to be cruel and insensitive (4, 8). This is also corroborated by our data (91%).

Half of the UHWI physicians interviewed did not seem confident in their communication skills, which might also be a factor in their reluctance to have discussions with their patients. Younger and more junior doctors, in general, felt less confident in their skills of communication as compared to their older colleagues. This is expected, as with more professional experience and confidence, doctors' communication skills should improve. It has been suggested that, ideally, communication with patients should be done with senior doctors (21). Additionally, no formal teaching is given to medical students or physicians on how to discuss difficult topics such as CPR and EOL issues with patients and their families. There may be an opportunity to improve the way medical personnel are trained in Jamaica so that they may be better equipped to talk with patients and their families about EOL concerns.

Interestingly, from the patients' viewpoint, only 40% of patients always found it easy to speak with their physicians. This number may reflect the difficulty people have speaking about death and dying, with its undercurrents of fear, compounded by a lack of time to build trust with the attending physician. Communication, being two-way, would be negatively impacted by patients' low comfort levels when asking questions. There have been significant changes in the doctor-patient interactions (22, 23) over the past decades with paternalism becoming unacceptable and easy access to medical information through the internet acting as a catalyst for change. However, locally there is a population of patients who still exhibit a reluctance to question their

doctors' opinions and/or advice. Questions and discussions are not generally entertained beyond the initiative of the doctors who may themselves be uncertain as to the timing of a discussion on EOL issues.

In keeping with the evidence presented by Brunetti *et al* (24) where only 13.5% of the physicians had executed a living will, we found that only 16% of our physician-respondents had done so. The argument that young doctors are not as yet in touch with their own mortality is weakened by the fact that older doctors in our sample population were also remiss in organizing their living wills. Therefore, it seems that there is a general apathy towards the subject and this should be discussed within the medical fraternity. Doctors apparently are reluctant to have EOL discussions with themselves.

Some of the limitations of this study included some sampling bias, with younger doctors and surgeons dominating the sample population and a disproportionate number of the haematology/oncology clinic patients. This is also a single-centred study, so our conclusions cannot only be applied broadly.

CONCLUSION

This study revealed that both physicians and patients supported the patient being the final decision- maker with regards to EOL issues. The patients desired more discussions with their physicians, but only in instances of complications or deterioration, not on general admission to hospital. The physicians reported having these discussions infrequently and being uncomfortable with their communication skills. The majority of the patients were also uncomfortable speaking with their doctors. Formal training in undergraduate and postgraduate courses should be introduced on communication with patients on potentially difficult issues such as advanced care planning (ACP). There is also a need for culturally specific guidelines addressing EOL discussions in an environment of severely time constrained physicians. The institution of appropriate ACP will likely reduce inappropriate CPR and the costs associated with administering life-sustaining treatment, which may be contrary to patients' wishes.

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