BMJ Open Knowledge, attitude and practice of community-dwelling adults regarding advance care planning in Malaysia: a cross-sectional study

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ABSTRACT

Objectives This study aimed to assess the knowledge, attitude and practice (KAP) among community-dwelling adults in Malaysia regarding advance care planning (ACP), and its associated factors.

Design This cross-sectional study was conducted from July–September 2018.

Setting This study was conducted at the University Malaya Medical Centre, Kuala Lumpur, Malaysia.

Participants We recruited community-dwelling adults (ambulatory care patients or their accompanying persons) who were ≥21 years old and able to understand English or Malay. A 1:10 systematic sampling procedure was used. Excluded were community-dwelling adults with intellectual disabilities or non-Malaysian accompanying persons. A trained researcher administered the validated English or Malay Advance Care Planning Questionnaire at baseline and 2 weeks later.

Primary and secondary outcome measures The primary outcome was the KAP regarding ACP. The secondary outcomes were factors associated with KAP.

Results A total of 385/393 community-dwelling adults agreed to participate (response rate 98%). Only 3.1% of the community-dwelling adults have heard about ACP and 85.7% of them felt that discussion on ACP was necessary after explanation of the term. The desire to maintain their decision-making ability when seriously ill (94.9%) and reducing family burden (91.6%) were the main motivating factors for ACP. In contrast, resorting to fate (86.5%) and perceiving healthy condition (77.0%) were the main reasons against ACP. Overall, 84.4% would consider discussing ACP in the future. Community-dwelling adults who were employed less likely to know about ACP (OR=0.167, 95% CI 0.050 to 0.559, p=0.004) whereas those with comorbidities were more likely to favour ACP (OR=2.460, 95% CI 1.161 to 5.213, p=0.019). No factor was found to be associated with the practice of ACP.

Conclusions Despite the lack of awareness regarding ACP, majority of community-dwelling adults in Malaysia had a positive attitude towards ACP and were willing to engage in a discussion regarding ACP after the term ‘ACP’ has been explained to them.

INTRODUCTION

Advance care planning (ACP) is defined as ‘a process that aids a person regardless of their age and health status to understand and share their personal values, life goals and preferences toward future medical care’. The concept which originated from developed countries has been implemented in these high-income countries to support patients’ end-of-life care. ACP aims to improve the quality of end-of-life care by enabling effective communication to ensure that care is concordant with an individual’s wishes particularly in the event when he or she loses the capacity to decide.

Well-implemented ACP policies may benefit patients (as they may experience a higher sense of autonomy and satisfaction with their care), their families (as they may experience less emotional stress, depression, burden and better quality of life) and the healthcare system (which may see a reduction in unnecessary hospitalisations and healthcare expenditures). Despite the known benefits of ACP, the uptake of ACP remains low due to failure to engage
patients when needed.\textsuperscript{2,14,15} The implementation of ACP may be challenging due to the multifaceted and complex decision-making process in end-of-life care, as a result of the conflicting needs and perception among patients, healthcare professionals and healthcare systems.\textsuperscript{1,16-18} Race, religion and cultural values have also been found to influence attitudes towards ACP, particularly among Asians.\textsuperscript{3,9-25} The Asian population account for 62.9\% of the world’s population.\textsuperscript{26} However, ACP in developing countries (of which Asia is no exception) is not well known. Less is known about the extent of their knowledge, attitude and practice (KAP) towards ACP, as end-of-life care in Asia is usually regarded as a culturally-sensitive topic.\textsuperscript{27-29} Discussion of death has been often a taboo as it is perceived to be ominous.\textsuperscript{21,30,31} The strong influence of the principles of beneficence and non-maleficence in Asian cultures tend to discourage talk about end-of-life decisions in order to avoid conflict and provide hope for the patients.\textsuperscript{32} The influence of religion may also vary between the different ethnic Asian groups, with more religious individuals prefer to leave the topic of death to fate as it is beyond their control.\textsuperscript{21} Asians have also reported to embrace collectivism in decision-making and are more comfortable making decisions with family due to their family-centric culture.\textsuperscript{28,29,33} This may include expectation of filial piety in their children, a highly regarded key virtue which may affect the decision on withdrawal of life-sustaining treatment for their terminally ill parents.\textsuperscript{34-36} Deferred autonomy is also reported to be the norm in Asia as patients are more likely to relegate their decision-making authority to physicians, who are regarded highly among Asians.\textsuperscript{30} In contrast, Western cultures are largely influenced by the principle of respect for individual autonomy which favours open discussions on end-of-life care and ACP.\textsuperscript{37} Thus, it is crucial to have a better understanding of the views of Asians in order to enable policymakers to navigate through the culturally-sensitive issues for successful implementation of ACP in Asian countries.

To date, there is a paucity of studies in developing countries to explore the views and readiness of primary care patients for ACP. Existing KAP studies on patients in the primary care setting were limited to developed countries or countries with enacted legislation such as Canada\textsuperscript{38} and China.\textsuperscript{36} Studies on ACP have been performed primarily in older or seriously ill patients such as patients with cancer, heart failure or end stage renal disease.\textsuperscript{14,39-47} The focus of prior studies on moribund patients could be a reflection of the reluctance of most stakeholders to engage in ACP earlier and preferred to delay until the issues were more clinically relevant.\textsuperscript{14,48} However, patients at advanced or terminal stage may be pressured to make an ill-informed decision.\textsuperscript{49} Thus, there is a rational proposition to shift the focus of investigation regarding ACP to the non-terminally ill ambulatory patients in the primary care setting as it is the first point of healthcare contact.\textsuperscript{48,49} Two prior studies on ACP in Malaysia that were conducted on older adults\textsuperscript{21} and patients undergoing haemodialysis\textsuperscript{50} reported low awareness regarding ACP. To date, ACP is not legislated in Malaysia and the KAP of community-dwelling adults in Malaysia has not been assessed.\textsuperscript{31} Hence, the aim of this study was to assess the KAP of community-dwelling adults and to determine its associated factors.

**METHODOLOGY**

This cross-sectional study was conducted from July to September 2018 at the University Malaya Medical Center (UMMC) in Kuala Lumpur, Malaysia. UMMC is a tertiary referral centre with 1617 beds. ACP is not performed routinely by any units in UMMC as ACP is not legislated in Malaysia. ACP services are only provided on an ad-hoc basis. We recruited community-dwelling adults (ambulatory care patients or their accompanying persons) who attended the primary care clinic at our setting, who were ≥21 years old and able to understand English or Malay. Excluded were community-dwelling adults with intellectual disabilities or non-Malaysian accompanying persons. The required sample size was estimated with the most conservative consideration, that is, when the proportion of the community-dwelling adults with the knowledge on ACP, p=50\% to obtain the largest sample size. Therefore, the sample size required with a confidence level of 95\% and ±5\% precision and 80\% power was 385.\textsuperscript{52} The main outcome measured was the KAP of community-dwelling adults towards ACP. The secondary outcomes were its associating factors.

**Instruments**

The validated English\textsuperscript{53} and the Malay Advance Care Planning Questionnaire (ACPQ)\textsuperscript{54} were used to assess the KAP. The ACPQ consisted of four domains: participant demographics, knowledge, attitude and practice of ACP. Questions such as ‘Do you know what is advance care planning?’ in the knowledge domain, ‘Do you feel that the discussion on advance care planning would be necessary?’ in the attitude domain and ‘Would you consider the discussion on advance care planning would be necessary in the future?’ in the practice of ACP domain were used to explore the patients’ KAP on ACP, respectively. After completion of the knowledge domain, a standard definition of ACP\textsuperscript{1} was provided to participants to maintain conformity. For the attitude domain, patients who were in favour of ACP were required to answer the items in the ‘justification for having ACP’ domain; while those who were not in favour of ACP, were required to answer items in the ‘justification for not having ACP’ domain. For the practice domain, patients who had intentions to plan for ACP were required to answer all remaining items in the practice domain.

**Procedure**

Systematic random sampling was conducted to reduce sampling bias. On each day of data collection, the researcher obtained a random number between 1 and 9 using a random number generator from the Math
Goodies Official Random Number Generator. Each patient was given a queue number on registration at the triage counter. The first patient was selected based on the random number generated on that day. A 1:10 systematic sampling procedure was used as approximately 300 patients attended the clinic each day, and one researcher could only recruit approximately 30 patients (or their accompanying person) per day. All eligible patients or their accompanying persons were approached and the purpose of the study was explained using the participant information sheet. For those who agreed to participate, written informed consent was obtained. Depending on the participant’s language preference, either the validated English or Malay ACPQ was administered by a trained researcher via face-to-face interview. Research-assisted administration of questionnaires was required because the ACPQ contained some medical terms that may require explanations. The time taken to complete the ACPQ was approximately 15–20 min.

Data analysis
Data were analysed with IBM SPSS V.22 (IBM Corporation). Normality was assessed using the Kolmogorov-Smirnov test. Since normality could not be assumed, continuous variables were presented as median and IQR, while categorical variables were presented as frequencies and percentage. The response of ‘do not know’ is an important finding as participants were not forced to either agree or disagree with statements if they ‘did not know’. Hence, do not know responses were reported descriptively. Preselection of factors for multiple logistic regression analysis was conducted using a bivariate logistic regression to assess the independent effects of relevant factors on the KAP after test of multicollinearity. Variables that reported a p value of <0.25 in the bivariate logistic regression was included in the multivariate logistic regression to isolate the effects of potential confounders.

Patient and public involvement
Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

RESULTS
Demographics
A total of 385/393 participants agreed to participate (response rate 98%). The majority were women (215, 55.8%) and Malay (148, 38.4%), with a median age of 61 years (range 22–88 years) (table 1). The most common comorbidities were hypertension (117, 30.4%), diabetes (103, 26.8%) and chronic kidney disease (25, 6.5%). No reason was provided for non-participation, and the researcher respected their decision by not asking for a reason.

| Table 1 | Participants’ demographic characteristics |
| --- | --- |
| Demographic characteristics | N (%) (n=385) |
| Median age (years) (range) | 61 (22–88) |
| Age<65 | 242 (62.9) |
| Age≥65 | 143 (37.1) |
| Sex | |
| Female | 215 (55.8) |
| Male | 170 (44.2) |
| Ethnicity | |
| Malay | 148 (38.4) |
| Chinese | 144 (37.4) |
| Indian | 93 (24.2) |
| Marital status | |
| Married | 309 (80.3) |
| Single/divorced/widowed | 76 (19.7) |
| Level of education | |
| Secondary (completed 12 years of education) | 224 (58.2) |
| Tertiary (completed at least 15 years of education) | 126 (32.7) |
| Primary (completed 6 years of education) | 35 (9.1) |
| Religion | |
| Islam | 148 (38.4) |
| Buddhism | 111 (28.8) |
| Hinduism | 76 (19.7) |
| Christianity | 50 (13.0) |
| Employment status | |
| Currently employed | 166 (43.1) |
| Non-employed | 219 (56.9) |
| Retired* | 162 (74.0) |
| Unemployed* | 57 (26.0) |
| Age | |
| Age≥65* | 132 (60.3) |
| Age<65* | 87 (39.7) |
| Personal income/month | |
| >RM1000 (US$240) | 268 (69.6) |
| ≤RM1000 (US$240) | 117 (30.4) |
| Living companion | |
| Living with someone | 349 (99.6) |
| Living alone | 36 (9.4) |
| Self-rated health status | |
| Good | 336 (87.3) |
| Poor | 49 (12.7) |
| Presence of comorbidities | |
| Cardiovascular disease | 131 (34.0) |
| Diabetes mellitus | 103 (26.8) |
| No underlying comorbidities | 53 (13.8) |

Continued
Knowledge

Only 12 participants (3.1%) have heard about the term ACP and 20 (5.2%) were familiar with the concept of ACP. The majority have not heard of terms related to ACP such as ‘surrogate-decision maker’ (361/385, 93.8%), ‘end-of-life decision making’ (346/385, 89.9%), ‘living will’ (220/385, 57.1%) and ‘durable power of attorney’ (290/385, 75.3%). Among those who have heard about the term ACP or terms related to ACP, participants reported that mass media (62/385, 16.1%) was their most common source of information, followed by friends (39/385, 10.2%), reading materials (32/385, 8.3%), relatives (26/385, 6.8%) and family doctors (12, 3.1%). Only 75 (19.5%) community-dwelling adults have thought of writing a living will and 23 (6%) community-dwelling adults had written a living will.

Attitude

A total of 330 (85.7%) community-dwelling adults felt that discussion on ACP was necessary and 331 (86.0%) agreed that ACP services should be provided in primary care clinics, after the term ACP has been explained to them. Majority (278, 72.2%) of the community-dwelling adults were willing to express their wishes if they had dementia (308, 80.0%), cancer (305, 79.2%), heart attack and on a breathing machine (283, 73.5%), or were in a coma (267, 69.4%).

Of the 385 community-dwelling adults, 311 (80.8%) were in favour of ACP. Justifications for favouring ACP were: ‘I am aware that I could possibly lose my decision-making power as a result of becoming seriously ill or injured’ (301, 96.8%), ‘I want to be able to make my own decisions’ (295, 94.9%) and ‘I hope to not burden my family with my medical treatment preferences’ (285, 91.6%). For those who were not in favour of ACP, the justifications were: ‘I will take it as it comes, I have no control over my death’ (64, 86.5%), ‘I am currently healthy and there is no need to consider such decisions’ (55, 77.0%) and ‘I felt that it was best to leave my future to fate or God’ (41, 55.4%) (table 2).

Practice

Of 385 community-dwelling adults, a total of 325 (84.4%) were willing to discuss ACP in the future. More than 80% of community-dwelling adults agreed that the topics for discussion to include cardiopulmonary resuscitation decision, the use of artificial breathing machine, tube feeding, place of death, haemodialysis, place of care and chemotherapy. In the event that they were unable to communicate their choices, majority of the community-dwelling adults chose their spouse (124, 38.2%) or family doctors (114, 34.4%) as their decision-making proxy.
members (122, 37.5%) to convey their wishes on their behalf while the rest of them prefer healthcare providers (77, 23.7%) or close friends (2, 0.6%) as their surrogate-decision-makers. In terms of recording their ACP, 277 (84.2%) of the community-dwelling adults preferred a verbal directive to family member or acquaintance. In addition, 221 (67.2%) were also open to the idea of a written documentation and to give the copy to their healthcare provider and family. However, audio or video tape recording was the least preferred choice with only 74 (22.5%) of the community-dwelling adults agreed to this method of recording.

Factors associated with KAP of ACP
Community-dwelling adults who were currently employed were less likely to know about ACP (OR=0.167, 95% CI 0.050 to 0.559) (table 3). This model explained 5% of the variance (F(6, 378)=3.307, p<0.05). Those with comorbidities were more likely to favour ACP (OR=2.460, 95% CI 1.161 to 5.213). This model explained 3.9% of the variance (F(6, 378)=2.568, p<0.05). However, no factor was found to be associated with the practice of ACP (F(4, 380)=2.568, p=0.051).

DISCUSSION
Awareness of ACP was low (5.2%) among community-dwelling adults in Malaysia. Despite the low awareness, community-dwelling adults in Malaysia (85.7%) had a positive attitude towards ACP after the term ACP was explained to them. In addition, 84.4% of the community-dwelling adults felt that ACP was necessary and would consider having a discussion on ACP.

Knowledge
Overall, the awareness of ACP was low among community-dwelling adults in Malaysia, where the majority have not heard about the term ACP. Interestingly, there were slightly more community-dwelling adults who were familiar with the concept rather than the term ACP, possibly due to the lack of publicity regarding the term ACP. When compared with other countries in Asia, older adults living in nursing homes in Hong Kong had similar awareness regarding ACP (4.0%). However, community-dwelling adults in Singapore were more familiar with ACP (14.4%) when compared with Malaysian community-dwelling adults. This may be due to lack of dedicated legislation or low public awareness of ACP in Malaysia and Hong Kong. Programmes to educate the public regarding ACP are mainly conducted by non-governmental organisations such as Hospis Malaysia (a charitable palliative care service provider), or ACP advisory service providers in an isolated manner. In contrast, national guidelines for palliative care and the Advance Medical Directive Act were enacted in Singapore in 2014 and 1996, respectively, which recommended that all terminally ill patients should have an advance care plan. This may have led to public discussions on ACP among the community dwellers in Singapore, thus increasing their awareness regarding ACP.

| Variables                     | B      | OR (95% CI)       | P value |
|-------------------------------|--------|-------------------|---------|
| Knowledge                     |        |                   |         |
| Hinduism                      | −0.255 | 0.585 (0.173 to 1.974) | 0.712   |
| Female                        | 0.646  | 1.907 (0.681 to 5.345) | 0.219   |
| Buddhism                      | −0.914 | 0.401 (0.108 to 1.483) | 0.171   |
| Age≥65                        | −0.875 | 0.417 (0.130 to 1.340) | 0.142   |
| Tertiary level of education   | 0.977  | 2.686 (0.949 to 7.434) | 0.063   |
| Employed                      | −1.787 | 0.167 (0.050 to 0.559) | 0.004*  |
| Attitude                      |        |                   |         |
| Female                        | −0.127 | 0.880 (0.477 to 1.625) | 0.684   |
| Christianity                  | 0.415  | 1.514 (0.500 to 4.585) | 0.463   |
| Monthly income ≤RM1000 (US$240) | −0.461 | 0.631 (0.332 to 1.198) | 0.159   |
| Buddhism                      | −0.469 | 0.625 (0.334 to 1.172) | 0.143   |
| No formal and primary education | −0.679 | 0.507 (0.207 to 1.243) | 0.138   |
| Has comorbidities             | 0.900  | 2.460 (1.161 to 5.213) | 0.019*  |
| Practice                      |        |                   |         |
| Buddhism                      | −0.179 | 0.836 (0.450 to 1.551) | 0.570   |
| Tertiary level of education   | 0.490  | 1.632 (0.837 to 3.181) | 0.150   |
| Hinduism                      | 0.684  | 1.983 (0.819 to 4.800) | 0.129   |
| Monthly income ≤RM1000 (US$240) | −0.484 | 0.616 (0.340 to 1.115) | 0.109   |
Attitude

Despite having a low awareness regarding ACP, community-dwelling adults in Malaysia had a positive attitude towards ACP after the term ACP has been explained to them. This result was similar to studies conducted in Hong Kong25 and Singapore26 where community-dwelling adults were more receptive to ACP when introduced to its definition and concept, indicating that knowledge and awareness could be a prerequisite to achieve a positive change in attitudes and belief towards ACP.26 64 Hence, awareness campaigns to help community-dwelling adults learn about ACP should be initiated using mass media, as mass media was the preferred source of information among Malaysians. The community-dwelling adults in our study also believed it was necessary for ACP to be provided in primary care clinics, which was similar to a study in Singapore which reported that 61% of the community dwellers would discuss ACP with their primary care physician.2 This suggests that community-dwelling adults were comfortable with discussion on end-of-life care in the primary care setting.

Reducing family burden and the desire to maintain their decision-making ability when seriously ill were the main motivating factors for those who were in favour of ACP in our study, as preference for healthcare autonomy may contribute positively to the attitude of planning ahead.36 The benefits of ACP in reducing the financial and emotional burden on the patients’ family could also persuade some to adopt positive attitudes towards ACP.2 14 On the other hand, ‘I am currently healthy’ and ‘I will take it as it comes as I have no control over my death’ were the main reasons given by those who were not in favour of ACP. This finding was corroborated by several studies in which ACP was deemed inappropriate and unnecessary for healthy individuals.65–67 A qualitative Malaysian study conducted in 2007 also showed similar findings whereby those who were unwilling to have ACP, wanted to leave these matters to fate or God.21 68

Factors associated with KAP regarding ACP

Non-employed community-dwelling adults were almost six times more likely to know about ACP than employed community-dwelling adults. This may be because an employed person may have lesser time to learn about ACP due to their job commitments when compared with unemployed persons. Additionally, an employed person may perceive ACP as less relevant due to their priority on their career.5 14 58 In contrast, retired and older unemployed adults may have a higher appreciation of end-of-life care-related matters leading to them spending more time to research about ACP.58

Community-dwelling adults with more comorbidities were almost 2.5 times more likely to favour ACP as compared with those who were healthy, which was similar to previous studies.58 63 Most community-dwelling adults believed that discussion about ACP was unwarranted when they are healthy as it may exert unnecessary burden on the family.14 64 Some community-dwelling adults also felt that it was irrelevant and irrational to raise discussion related to end-of-life care during normal consultation on minor ailments with their physicians.64 Hence, diagnosis of chronic conditions which may lower their perceived level of healthiness, possibly eliminating the barrier of perceived irrelevance of ACP.58 64 This is congruent with previous studies describing that discussions on ACP or end-of-life care often occur when an individual is in the advanced stages of a disease. Although 30.4% of the participants had a monthly income <US$240, the low level of income did not influence their attitude towards ACP. Our finding was different from the findings of previous studies76–78 which reported better engagement towards ACP among community-dwelling adults with higher income. The difference in observation may be due to individual incomes (asked in our study) versus household incomes in other studies.76–78

No factor was found to affect the practice of community-dwelling adults in Malaysia on ACP. A possible explanation could be due to limited access and exposure to ACP and its concept in Malaysia. ACP is mainly promoted by non-governmental organisations promoting palliative care in the country without the support of legislative instruments and an established ACP framework or professionals. This may be due to the fear of blindly entering a legally binding advance directive. Our findings were consistent with other studies from Malaysia,21 Singapore,58 Hong Kong,57 Japan, Korea and China.24 Previous study has also described Asians favouring family-centric decision-making in which most of them chose their family to make medical decisions for them when they become incapacitated, even if they have migrated to non-Asian countries.75 This is probably due to strong trust and bonding between family members. Reciprocally, Asians were also more likely to forgo treatment of themselves rather than their family members, when they are in a terminal stage because it is unacceptable to be accused of unfilial for not treating their elderly parents.36

Practice

Malaysian community-dwelling adults were as willing as Singaporean community-dwellers (81.8%) to begin ACP discussion with their primary care physicians.2 In comparison to studies conducted in western countries, our findings were significantly lower compared with studies conducted in Ireland63 and in Australia.70 Asians may be less willing than non-Asians to discuss end-of-life-care for several reasons. Talking about ACP is a societal taboo among Asians70 as discussing about death or dying may bring bad luck and hence, this topic should be avoided.71 Moreover, making end-of-life decisions is thought to hasten death.72 With the lack of discussions about death and end-of-life care, it is not surprising to see the lack of communications on ACP among Asians compared with non-Asians.73 From our results, verbal directive to family members was the preferred method in conveying their wishes in advance, and family members were the ideal surrogate decision-makers rather than healthcare
system. The lack of guideline, protocol and system may result in patients’ hesitation to commit to ACP until better clarity about its undertaking. Proper protocol with regulatory guidelines to promote protection of patients’ interest, and clarity on the roles of various professionals and organisations pertaining ACP to ensure smooth conduct of ACP may help to remove the patients’ doubts and thus, persuade them to initiate discussions on ACP.

While prior studies have described the influence of religion on preference for ACP, we were not able to see any association in our study. Literature suggests that individuals with strong religious belief would have a negative attitude towards planning for end-of-life related matters due to their desire to leave these matters to fate. However, most of the community-dwelling adults in this study were receptive to the concept of ACP. This may be due to the western influences, and the Malaysian culture of accommodation and openness to new ideas.

One of the limitations of our study was the recruitment of community-dwelling adults from a single site which may affect the generalisability of this study. Recruitment from multiple sites should be considered in future studies. Second, acquiescence bias as a result of interviewer-assisted questionnaires cannot be ruled out. Third, the knowledge regarding ACP among the community-dwelling adults was self-reported by answering one question. The questionnaire used was designed as a preliminary assessment among populations which has low awareness regarding ACP because assessment of knowledge with a test would not be possible due to the low awareness. Despite the limitations, baseline findings from this study can assist policy-makers to decide if Malaysians are ready for ACP to be legislated in Malaysia. Moreover, the participants in this study were recruited using systematic random sampling method to reduce sampling bias. Another strength of this study was the use of a validated questionnaire to assess the community-dwelling adults’ KAP towards ACP to minimise the risk of acquiescence bias.

CONCLUSIONS

Despite the lack of awareness regarding ACP, majority of community-dwelling adults in Malaysia had a positive attitude towards ACP and were willing to engage in a discussion regarding ACP after the term ACP has been explained to them. Community-dwelling adults who were employed were less likely to know about ACP whereas community-dwelling adults with comorbidities had a more favourable attitude towards ACP. No factor was found to be associated with the practice of ACP. Findings from this study can be used to inform the writing of guidelines, and legislative frameworks regarding ACP. Efforts to raise awareness regarding ACP in Malaysia can be directed to the community-dwelling adults with comorbidities using mass media.

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