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Preparing Older Patients with Serious Illness for Advance Care Planning Discussions in Primary Care

Nebras Abu Al Hamayel, MBBS, MPH, DrPH¹, Sarina R. Isenberg, PhD^{2,3}, Joshua Sixon, BS¹, Katherine Clegg Smith, PhD⁴, Samantha I. Pitts, MD, MPH⁵, Sydney M. Dy, MD, MS¹, Susan M. Hannum, PhD⁴

¹Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA

²Temmy Latner Centre for Palliative Care and Lunenfeld Tanenbaum Research Institute, Sinai Health System, Toronto, Ontario, Canada

³Department of Family and Community Medicine, University of Medicine, Toronto, Ontario, Canada

⁴Department of Health, Behavior and Society, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD, USA

⁵Department of Medicine, Johns Hopkins School of Medicine, Baltimore, MD, USA

Abstract

Context—Little is known about how to prepare older patients for advance care planning (ACP) discussions in primary care.

Objectives—To explore older patients' perspectives and experiences on ACP discussions with family members and/or primary care clinicians.

Methods—We conducted a qualitative interview study with 20 older patients who were involved in the clinic's ACP quality improvement initiative. We used an inductive approach to generate a coding scheme and used thematic analysis alongside a constant comparative methodology to iteratively refine emergent themes after coding the data. We used the transtheoretical behavior change model to conceptualize the process of ACP discussions, focusing on the contemplation, preparation and action stages.

Results—Four key themes emerged from our analyses: (1) the relevance/importance of ACP as a whole; (2) independently conceptualizing wishes and preferences for the future; (3) the process of engagement in ACP discussions; and (4) different outcomes of ACP discussions. While patients contemplated having an ACP discussion, they needed time to conceptualize their wishes on their own before documenting wishes or engaging with others. Moving to the preparation stage, patients

Corresponding author: Nebras Abu Al Hamayel; 624 N Broadway St. Room 610, Baltimore, MD, 21205, USA; phone: (202) 423-6559; nabualh1@jhu.edu.

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shared their perspectives about how to engage family members and primary care clinicians in ACP discussions and reported different outcomes of these discussions, which varied according to patients' goals for ACP.

Conclusions—Understanding how to best prepare patients for ACP discussions from patients enrolled in an ACP primary clinic quality improvement initiative may assist primary care practices in developing interventions to improve the occurrence and effectiveness of such discussions.

Keywords

advance care planning; advance care planning discussions; advance directives; patient-centered communication; primary care; qualitative research

INTRODUCTION

Advance care planning (ACP) is the process of communication between a patient, family member, healthcare agent, and/or clinician to clarify treatment preferences and to develop goals for future care. (1) Ideally, ACP includes discussions over time to explore patient preferences and values, choose a healthcare agent, and complete an advance directive (AD). (2) ACP discussions and effective communication about future care have been clearly shown to increase the likelihood that patients will receive care consistent with their preferences. (3) However, it is common for these ACP discussions to not occur, or only occur when patients are seriously ill. (4–8) Only 61% of older adults have reported talking to a family member or friend about their preferences for medical treatment if they become seriously ill in the future; less than 1% of Medicare beneficiaries have reported having an ACP discussion with their primary care clinician. (4, 7) A common barrier to ACP is that patients are not prepared or ready to engage in these discussions. (9) Better understanding of patients' readiness to engage in ACP discussions could inform interventions to increase likelihood of occurrence and improve communication between patients and their primary care clinicians.

Primary care is a key setting for ACP for several reasons. (10) Older patients generally prefer discussing future care with a clinician who they trust and with whom they have a longstanding relationship, and primary care clinicians are often best poised to understand patients' individual preferences and values, and to deliver care consistent with those goals. (11) Patients also prefer to have ACP discussions with their family and/or clinician early, before they may be acutely ill or hospitalized. (11, 12)

The process of ACP discussions can be conceptualized into five discrete steps based on the behavior change (transtheoretical) model, which has been used by clinicians and researchers to promote ACP and inform ACP interventions. (13–15) Applying this framework to the process of ACP discussions, these five stages are: (1) pre-contemplation (patient is not aware or not willing to engage in ACP discussions), (2) contemplation (patient develops intentions to engage in ACP discussions), (3) preparation (patient commits to having an ACP discussion), (4) actions (patient discusses ACP with family members and/or clinicians), and (5) maintenance (patient repeats ACP discussion and/or updates AD). Patients may be at different stages of readiness to engage in ACP discussions, which may serve as a basis for targeted interventions to achieve ACP discussions. (14) In this study, we focus on the

contemplation, preparation, and action stages for ACP discussions among older patients involved in a clinic ACP initiative in a primary care setting to explore older patients' perspectives and experiences on ACP discussions with family members and/or primary care clinicians.

METHODS

Subjects and Study Design

For this qualitative study, we conducted semi-structured, qualitative interviews with 20 patients aged 60 or older in an academic suburban primary care clinic from June through August 2016. All patients 60 or older, who did not have an AD or similar documentation in their electronic health record and had a scheduled annual visit with their primary care clinician, were included in the clinic's ACP quality improvement initiative. Patients were mailed a letter about ACP and an AD prior to their annual visit to discuss ACP with their family or friends and with their clinician during their upcoming visit. The letter also encouraged patients to complete the enclosed AD form and bring it with them for their next visit. At the visit, clinicians were reminded to bring up ACP with the patient. Further details about the initiative and how it was implemented are published elsewhere. (16, 17)

We used a convenience sample from all patients who were involved in the initiative and had annual visits during the study time period. We included patients who were willing to participate in a 30-60 minute interview and were able to speak English. We obtained informed consent before the start of the interview and offered patients a \$25 gift card for participation. This study was approved by the Johns Hopkins Bloomberg School of Public Health Institutional Review Board.

Data collection

We conducted in-person 30-60 minute interviews using a semi-structured interview format. The interviews focused on perspectives of older people on the quality of serious illness care (17); this paper focuses on the portion of those interviews relating to patients' perspectives of and experiences with ACP where patients raised issues specific to ACP that require further understanding and interpretation. We developed the interview guide based on systematic reviews of satisfaction and quality improvement in palliative care with input from two patient advocates (see Appendix for this portion of the guide; details of the full interview guide are described elsewhere (17)). Since this was a one-time interview, we used a semi-structured approach to explore patients' perspectives systematically while allowing for flexibility to explore emergent topics of importance to participants. (18) In most interviews, two research team members (One senior and one junior researcher) were present with one to take notes, which were used in the analysis process. We informed patients about the researchers' roles in interviewing and notetaking. All interviews were audiotaped and transcribed verbatim by an independent, licensed transcriptionist.

Data analysis

We used an inductive approach to generate codes that captured patterns in the data and that were related to our research question. The codebook went through several revisions as new

data were being collected until a final codebook was formulated. Transcripts were coded using MAXQDA 12, version 12.0 (Berlin, Germany). (19)

We used thematic analysis alongside a constant comparative methodology to iteratively refine emergent themes after coding the data. (20, 21) N.A. analyzed each interview individually and then compared each interview to all other interviews to identify emergent themes related to patient perspectives of and experiences with ACP. We identified initial themes using the coded data, field notes, and summaries of the interviews. We then shared these themes with all other research team members, two of whom (S.D. and S.P.) were involved in the quality initiative and two of whom (S.H. and K.S.) are experts in qualitative research. We went through several iterations, incorporating research team feedback and constructing meaningful interpretations of those themes that relate to our research question. (22) We used the transtheoretical model to help align our findings with the process of ACP discussions.

We used several strategies to ensure quality and trustworthiness of our analytic process. (23) We developed a codebook to ensure patterns in the data are identified in a systematic manner. Two independent coders (N.A. and S.R.I.) coded 20% of all transcripts independently and then resolved discrepancies by discussion and consensus to ensure intercoder consistency and the stability of the developed codes.

RESULTS

Our sample of 20 patients had a mean age of 70.6 years, was 65% female and 25% African American; 75% had at least one chronic condition and 20% had a history of cancer. Four key themes emerged from our analyses that describe patients' perspectives on the process of ACP discussions with their family members and/or primary care clinicians: (1) the relevance/importance of ACP as a whole; (2) independently conceptualizing wishes and preferences for the future; (3) the process of engagement in ACP discussions; and (4) different outcomes of ACP discussions. We present themes, subthemes, and illustrative quotations in Table 1.

1. The relevance/importance of ACP as a whole

Patients were aware of the relevance/importance of ACP as a whole process that includes both discussions with family members and/or primary care clinicians, and completion of ADs or similar forms. Generally, patients thought it was important to think about their end-of-life wishes and start planning sooner rather than later, when they are not able to make decisions for themselves. This thought process entailed having discussions about wishes and future illness with family members and primary care clinicians in advance of preparing these documents.

Patients expressed that family members were not always open to such discussions, but that it was critical to share and inform family members about their wishes to ensure that care is consistent with those wishes. Patients wanted to have discussions with their primary care clinicians and thought it was important for primary care clinicians to initiate those discussions. Although patients considered the importance of completing an AD related to

their perceptions of the usefulness of documenting care preferences, some patients were concerned about how ADs are used in care and that they do not guarantee that care is consistent with patients' wishes, which supports the importance of having an ACP discussion with close family members and primary care clinicians.

2. Independently conceptualizing wishes and preferences for the future

Patients expressed a preference to first think about their wishes and preferences for the future on their own prior to discussing them with family members and/or primary care clinicians, which helped prepare patients for these discussions. Patients thought that the clinic's approach to sending the ACP letter and AD form in the mail helped prepare them for the next visit to discuss ACP with their primary care clinician.

There were many factors that helped patients to develop their initial preferences prior to them discussing them with others. Most commonly, personal values helped shape patients' preferences. Patients expressed not wanting extreme measures or interventions if they were not getting better, but still wanted to be kept comfortable. Patients highlighted quality of life as a central concept for their preference for refraining from extreme measures. Patients also valued being at home and surrounded with loved ones rather than being in a hospital or a nursing home. Although not a primary preference, some patients considered long-term health care at a facility than having care provided at home. Less commonly, wishes and preferences were discussed in the context of spirituality and prolonging life.

Another important factor was patients' personal experiences; patients referenced experiences with medical illness or with loved ones' experiences of dying to clarify wishes and preferences, and drew hypothetical situations for if they were very sick to help draw their preferences for future care. Further, aging and the consequences of aging (e.g., being forgetful) motivated patients to begin exploring their wishes and preferences, and patients' career field, specifically those in medicine or law, which made them more aware of issues that could surface if preferences were not considered early.

3. Process of engagement in ACP discussions

Patients described preferences about different levels of engaging i) family members and/or ii) primary care clinicians and how to engage them, which may help meet the needs of patients in different levels of preparedness.

i) Engaging with family members—Although patients thought it was important to have discussions with family members including children and spouses, they thought it was often difficult to do this. Patients focused predominantly upon discussions with their children. Some patients reported that their children did not want to engage in such discussions due to emotional concerns; however, their children eventually understood the importance of these discussions. Some patients had formulated their wishes and preferences on their own and only wanted to inform their children to make them aware about their wishes. A few patients were at a stage where they wanted to engage in discussions with their children to help formulate their own wishes.

ii) Engaging with primary care clinicians—Most patients had interacted with their primary care clinician about ACP as part of the initiative. Clinicians mostly asked patients about AD forms, which were sent out to patients as part of the clinic's ACP initiative. Patients indicated that they did not often have a detailed discussion regarding their preferences and values of care with their primary care clinician; however, they expressed that they were open to discussing ACP with their primary care clinician and felt comfortable with their primary care clinician initiating the discussion, especially in the context of a long-standing relationship. Some patients preferred to approach clinicians for clarification regarding terms in the AD form and choices.

At a pragmatic level, patients indicated that during visits, they often had medical issues to address, which prevented or limited patient-clinician ACP discussion. In instances where time limited ACP discussions, patients appreciated when clinicians indicated they would discuss ACP at a subsequent visit, which helped prepare patients before the visit.

4. Different outcomes of ACP discussions

Patients highlighted that ACP discussions were often used as a bridge to achieve different outcomes. Acknowledging patients' differing ACP discussion outcomes may help prepare patients regarding the nature of the discussion. Three subthemes emerged including: i) formal documentation of health wishes; ii) revisiting wishes and updating future plans, and iii) selecting a health care agent.

i) Formal documentation of health wishes—ACP discussions helped many patients put their wishes in writing as a formal document. For other patients, they felt these discussions were especially important when they were reluctant to document wishes and preferences on their own. Patients worked with clinicians or trusted attorneys, who they were familiar with, to assist them in documenting their health wishes. One patient mentioned how terms on the AD forms were sometimes complicated and too specific, and thus they needed help from a primary care clinician in order to complete it.

ii) Revisiting wishes and updating future plans—Some patients' ACP discussions involved revisiting their wishes and future plans and resulted in patients either re-conceptualizing their wishes or redoing their AD. These changes were motivated by life circumstances changes, such as having a health agent or power of attorney move away, pass away, or become sick. Patients also revisited their wishes and preferences at the end-of-life after experiencing the death of a loved one. Other patients did not see the need to change their wishes and felt that their values and decisions had not changed.

iii) Selecting a health care agent—Discussions with family members often served as a trigger for patients to search and choose a health care agent. Patients expressed their feeling of trust towards an individual informed who they chose as a health care agent: someone that knows what is important to the patient and will follow the patient's wishes. Patients thought that if they were unable to make decisions for themselves, their health care agents' input and decisions would override the contents of the AD. Thus, choosing a health

care agent that they could trust was crucial to patients if they became incapable of making moment decisions and when emotions of loved ones interfere with known wishes.

DISCUSSION

Our study reveals four key themes that represent experiences of older patients on the process of ACP discussions with family members and/or primary care clinicians. While patients are aware of the importance/relevance of ACP as a whole process that encompasses discussion and documentation of end-of-life wishes, they need time to conceptualize their wishes on their own before documenting wishes or engaging with family members and primary care clinicians. Patients also shared their perspectives about how to engage with family members and primary care clinicians in ACP discussions and reported different outcomes of these discussions, which varied according to patients' goals for ACP. These themes may overlap and may not be applicable to all patients, depending on the extent of patient engagement with the ACP discussion process.

Various studies have focused on completion of AD and formal documentation of wishes and preferences in the primary care setting.(24) However, few studies have focused on understanding older patients' perspectives on ACP discussions in primary care or the experiences in quality improvement initiatives, which precedes completion of an AD. (15, 25) We argue that these four key themes fall into the contemplation and preparation stages of the transtheoretical model. Focusing on these four themes may help move patients from contemplating to preparing to discussing ACP with family and/or friends and clinicians and actions of completing ADs. (15)

In this study, patients have contemplated having an ACP discussion by being aware of the relevance/importance of discussions about future care as part of the ACP process as well as early timing of discussions when the patient is in good health. Although patients were aware of the importance of family discussions, there was a preference for thinking about one's own wishes, values, and quality of life before sharing it with family members. Moreover, patients mentioned personal experiences that contributed to their conceptualization of future care, which are similar to previous studies that explored the patient and/or health care agent perspective on care preferences and future decision-making. (26–28) It may be inferred that patients often need their own space and time to reflect on future decisions without family interference. Other studies have provided evidence that family members of older patients may not be welcoming or accepting to conversations about the future care of their loved ones or lack close family relationships, which are known barriers for ACP discussions. (29)

Moving from contemplation to the preparation and action stages of the transtheoretical model, patients described how they have or would engage their children in ACP discussions, with emotional concerns being a reason for not engaging. It is imperative for primary care clinicians to inquire about patients' preferences for conceptualizing their own wishes in an objective manner and to inquire about desired family involvement in preparation for an ACP discussion in the future. Primary care clinicians may also be able to help with emotional patient-family discussions about these issues.

ACP discussions can be challenging and difficult for patients, family members, and clinicians. (30) The majority of patients in our study expressed their willingness to have those conversations with their primary care clinician. Similar to other studies, trust and being known to a clinician were facilitators to having an ACP discussion. (11, 31) When ACP discussions did not take place during the clinic visit, patients valued their clinician's suggestion for having a conversation in the next visit. (32) As patients move in the cycle of the process of ACP discussion, nudging patients may be a way to help prepare patients for those discussions.

As ACP discussions have several purposes and may occur over time, clinicians should account for patients' perceived outcomes of ACP to help navigate patients' readiness for having a conversation. Although the main goal of the clinic's ACP initiative is to increase completion of AD forms, ACP discussions were key for formal documentation of preferences for future care. Patients also viewed ACP discussions as an ongoing process that allowed them to revisit wishes and update future plans, and choose a health care agent they trust, which is an important factor in effective ACP. (27)

Traditionally, many ACP initiatives have focused on patients with serious and terminal illness and have focused on the healthcare system and clinician barriers for ACP discussions. (33, 34) Our study complements past work that suggests ACP should be incorporated into primary care practice. (30, 35) From a patient perspective, our study demonstrated that a diverse patient population with varying degrees of illness and comorbidities were open to ACP discussions with their primary care clinician. Efforts to incorporate ACP discussions in primary care practices may be more effective when considering patients' perspectives on ACP discussions to help prepare patients for these discussions.

The main strength of our study is the use of in-depth and rich data, which provide insights into patients' perspectives on ACP discussions. We used several strategies to ensure quality and trustworthiness of data including assessing the stability of our coding system and intercoder consistency, and using debriefing sessions and regular meetings with the research team to aid in data analysis. (23, 36) Our study also has some limitations. In particular, our patients were recruited from an academic primary clinic with an ACP quality improvement initiative, and thus experiences may be different in other community-based clinics or similar academic primary clinics without an ACP initiative. We narrowed our research question to patients who are enrolled in an ACP initiative to gain a deeper understanding of patients' views on how to prepare them for having an ACP discussion, which led to rich and informative data. Our sample was limited to English speakers and Whites and African Americans, and thus other patients might have had different cultural considerations that might have influenced patients' experiences or perspectives about ACP discussions.

CONCLUSIONS

We present four themes as a thematic basis for informing quality improvement initiatives and ACP discussion interventions: (1) the relevance/importance of ACP as a whole; (2) independently conceptualizing actual wishes and preferences for the future; (3) the process of engagement in ACP discussions; and (4) different outcomes of ACP discussions.

Understanding how to best prepare patients for ACP discussions from patients enrolled in an ACP primary clinic quality improvement initiative may assist primary care practices in the development of interventions to improve the occurrence and effectiveness of such discussions and improve best practices for ACP discussions. Incorporating the patient perspective and considering the transtheoretical model in ACP initiatives may also improve patient-provider communication and patients' interactions with the healthcare system. Further research is needed to study how best to prepare patients for ACP discussions and formal documentation of wishes and improving ways to empower patients and families to think about, discuss and document their future care goals.

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Appendix:: Abbreviated interview guide

1. Have you imagined a time where you were sick and couldn't talk or make treatment decisions for yourself?
2. Have you been asked or informed about planning for future illness? If yes, how were you informed?

*Probing questions: Did you receive a letter from the clinic? Have you watched a video about this or any other educational materials? How do you prefer to be informed about this?
3. Have you ever discussed your future care plan with your provider?

*Probing question: Would you feel comfortable discussing your future plans with your providers?
4. Have you written or signed anything to make your wishes known such as an advance directive plan? Do you have an advance directive or any other formal documentation? How frequently would you be comfortable updating it?
5. What do you see as the main gaps in quality of care related to advance care planning and/or care in general? What are some of the barriers of having high-quality care?

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Table 1.

Themes and subthemes describing patients’ perspectives on advance care planning and sample quotations

Theme/subtheme	Quotation
1. The relevance/ importance of ACP as a whole	<p>“I’d rather deal with it now when I have all my faculties than later when I might be in distress and maybe not in a good frame of mind and maybe not pick the right result. The right decision.” (76, M) “With respect to my own, I made sure that I have advanced directives and I’m talking to my children and letting them know. I will do exactly what my own parents have done because I see many other people who have no idea; they just haven’t shared anything. It’s very important! People need to talk; they need to let other people know what their plans are.” (62, F)</p> <p>“I think doctors should be fully able to discuss all alternatives and all outcomes with the patient and be realistic about it and not engage in anything misleading. I think that end-of-life planning is extremely important and everyone should have to do it because you need to think about your own mortality. If you don’t consider your own mortality, you are fooling yourself and I think it’s dangerous because when you do experience a disease or a condition, which leads to the end of your life, you’re not able to deal with it in the same way. So I think that getting doctors to deal with death is really important.” (76, M)</p> <p>“For the millennial[s] especially, they don’t want to hear it. They don’t want to talk about it. But, you have to make them aware.” (65, F)</p> <p>“I think, they [AD] serve a purpose, they help the patient, clarify for him or herself what it is that they want, which I suppose can be reassuring to know that you thought those things through. How much that translates to what care is that you receive, I don’t know. I’ve only had my mom’s experience and my own, where I was mostly deeply offended that she was asking about ADs cause I wasn’t planning on going anywhere.” (63, F)</p>
2. Independently conceptualizing wishes and preferences for the future	<p>“It’s hard to be very specific to say we’re going to do it this way and it’s going to work. People have to come to terms with that on their own. You know, I think having it, presenting it to the patients, giving it to them, letting them have it, reminding them if they haven’t done it periodically. You know, we gave you the advanced directives; you haven’t given it back, have you thought about it? That’s how I would like for it to happen to me.” (70, F)</p> <p>“Like, one of my co-workers had lung cancer and she went through the chemo and all of that and she lost all the weight and at some point she just told them ‘Stop. I’ve had enough.’ I think that’s how I am. If you know you can’t cure me then stop putting me through all this and just let me go peacefully. So I mean, all of us want to live forever, but I think the quality of life is very important.” (70, F1) “I’ve been aware of advanced directives for many years and I’m not sure how or why. It may have been on connection with my father and his death or maybe my mother. I’ve been aware for a number of years and I was glad to get it in the mail. I was just glad to get my hands on it because I’ve been wanting something like that.” (70, M)</p> <p>“We had signed up for long-term care. If we could’ve afforded to have somebody at home, we’d have had somebody at home. I’d rather be at home.” (88, F)</p>
3. The process of engagement in ACP discussions	
<i>i) Engaging with family members</i>	<p>“She [referring to her daughter] doesn’t want to hear that mom could die and she said, ‘I don’t want to hear about you dying, mama.’ But, I’ll just make my wishes be known.” (70, F)</p> <p>“I feel like we would be on the same page. It’s a conversation we could have. Next time she comes home when it’s quiet.” (63, F)</p>
<i>ii) Engaging with primary care clinicians</i>	<p>“We [patient and primary care clinician] just dealt with it like we deal with everything because over the course of time you kind of build that kind of relationship.” (64, M)</p> <p>“So she [primary care clinician] explained it to me and she filled out the form as I explained different things.” (69, M)</p>
4. Different outcomes of ACP discussions	
<i>i) Formal documentation of health wishes</i>	<p>“We [patient and primary care clinician] went over that [advance directive] today. I’ve had advance directives for 30 years or whatever but I had to qualify a couple of things on it because I wasn’t 100% sure on the wording; just because of the form.” (69, M)</p>
<i>ii) Revisiting wishes and updating future plans</i>	<p>“I have updated it [advance directive] twice. The first time, my husband was the decision maker and then he got sick. So I had my son, who’s also a physician, as the decision maker but then he moved. So he’s not accessible, you can’t reach him, and he can’t be there to assess the situation so I changed it to one of my other sons.” (71, F)</p> <p>“After my mother’s experience I really want to look at it [advance directive] again because I want things to be more precise. I don’t want to live my life on a respirator and you know if that’s what’s keeping me alive but I don’t want to be left on the floor either so I think the terms have to be tightened up a little because she had an advanced directive and that’s what they were using and the terms obviously weren’t tight enough.” (78, F)</p> <p>“Once you make them [referring to wishes], you get invested in them, you don’t want to change them.” (63, F)</p>

Theme/subtheme	Quotation
<i>iii) Selecting a health care agent</i>	“The healthcare directive, and maybe it’s my own interpretation, when I look at it, it’s a list of suggestions. The ultimate decision is the named advocate for you. They know what you prefer, but if they ultimately decide something different, it’s because you trust them. You’re naming them and you trust their decision.” (71, F) “The bottom line is you can do advance directives and people that care about you are going to do what they want unless you’ve got somebody who is really going to enforce it.” (63, F)

ACP: advance care planning; F : female; and M: male.

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