



Exploring perceptions of online calculators for identifying community-dwelling older people at risk of dying: A qualitative study

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ABSTRACT

Objectives: This study aimed to assess the acceptability, value, and perceived barriers of using electronic risk calculators for predicting and communicating the risk of death in community-dwelling older adults.

Methods: One focus group and eight interviews were conducted with 16 participants with experience caring for patients or family members at end of life. A prototype mortality risk tool was used to anchor discussions. Data were analysed using a qualitative content analysis approach.

Results: Five themes emerged: acceptability, communication, barriers to use, broadening the circle of care, and tool limitations. Participants found the tool helpful for preparation, planning, and providing care, but disagreed on its community availability. Personalized risk estimates were valued for facilitating early goals of care conversations and normalizing discussions about death. However, concerns were raised about the tool's interpretation for individuals with different language, cultural, or educational backgrounds.

Conclusions: While electronic risk calculators were found to be acceptable, balancing autonomy with varying preferences for receiving the information and potential need for support is crucial.

Innovation: Providing patient-oriented life-expectancy estimates can enhance decisional capacity and facilitate shared decision-making between patients, their families, and healthcare professionals. Further research is needed to explore effective communication of personalized risk tools and additional benefits, harms, and barriers to implementation.

1. Introduction

For patients who are approaching the end of their life, home is often reported as the preferred place of care [1-4]. In developed countries, however, this commonly does not happen (due to social and structural influences [5-7]) and healthcare towards the end of life places major resource burdens on acute health care systems, such as hospitals [4,8]. As well as cost, the quality of end-of-life care is a growing priority for the public and for patients and their families, and this includes being cared for and dying in the place of their choice [4,9]. Underlying these observations is a gap in the delivery of palliative and end-of-life care, particularly in the home [10]. Identifying persons with life-limiting chronic illness earlier in their disease trajectory is essential to delivering quality end-of-life care and has been identified as a significant success factor in positive patient, family and system outcomes [11-13].

Various societal and cultural factors impact access to palliative care, including reluctance of family members to discuss palliative care. Sharp et al. found that the majority of frail and older individuals want to discuss end-of-life care but most do not have the opportunity [14]. Family resistance, reliance on others' decisions, and uncertainty regarding future illness and decline were identified as barriers to end-of-life care conversations [14]. There are also professional barriers for identifying patients who would benefit from palliative care earlier in their healthcare journey. Providers have difficulty identifying older patients who are at risk of dying and are often reluctant to initiate end-of-life conversations, especially in the absence of a precipitating event [11,14-17].

There has been a movement towards patient-centred care with active collaboration and shared decision-making between patients, families, and care providers. Patient-centred care responds to individual patient

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preferences, needs, values and goals and has long been recognized as a desirable attribute of health care [18]. Patient-centred interventions directed at patients, clinicians or both are supporting patients and clinicians before, during and after encounters and are improving communication and health outcomes [19,20]. The use of patient-oriented electronic predictive risk calculators ('risk calculators') has been suggested as a potential tool to support patient-centred end-of-life care planning. However, little is known about the acceptability and feasibility of using such tools in the community setting.

The objectives of our study were to examine patients', families' and health care providers' views on 1) identifying people in the community who are nearing the end of life; 2) the potential role for an end-of-life risk prognostication tool to improve advanced care planning discussions and end-of-life care; 3) preferences and challenges for an online end-of-life risk tool in the community setting; and 4) limitations of such a tool and how it could be improved.

2. Methods

This study was approved by the Ottawa Health Science Network Research Ethics Board (File 20,150,639-01H). This qualitative descriptive study used focus groups, supplemented by one-on-one interviews with patients, families, and health care providers.

2.1. Prototype development

To help anchor discussions, we developed a prototype tool for predicting mortality risk among community-dwelling older adults that spans an actionable period for end-of-life planning (five years to imminent death). The tool's underlying algorithm, which provided the mortality risk prediction estimates, was derived and validated using population-based home care data and included exposures that could be reported by patients and their caregivers, including family members [21,22]. The prototype was designed to be used by patients, family or friend care givers as well as health care professionals. Using the responses to questions about their health and ability to care for themselves, the tool provided an estimate of a person's survival based on information gathered on people who have similar characteristics. The tool featured a user-friendly interface with straightforward language and presentation of risk in multiple formats (e.g., relative risk, median life expectancy, 1-year absolute risk) with visualizations to aid understanding.

The tool, intended to facilitate discussions about the care needs of frail older adults, would be openly available online. The intent is to not replace the relationship between a patient and their healthcare providers, rather, to support a model of care that emphasizes shared decision making, where patients' needs and preferences are informed and at the centre of care-related discussions. The tool is part of an active program of research around end-of-life care and this study represents early evaluation regarding the provision of risk estimates for the public's use.

2.2. Sample recruitment

Members of the study team [DM, PT] identified a purposeful sample [23] of English-speaking informants, from the province of Ontario, Canada. These informants were identified and selected because of their experience caring for patients or family members at end-of-life. The team also recruited additional subjects through public advertisements in local clinics and hospitals. Subjects who were interested in participating either provided information to be contacted by the research coordinator (if identified by a member of the study team) or contacted the research coordinator directly via email or phone. The research coordinator [SB, KP] provided a study information sheet and consent form. Participants were then scheduled for a focus group [24]. For individuals unable to attend a focus group due to scheduling conflicts, an interview time was arranged.

2.3. Data collection

A study team member experienced with qualitative research methods conducted the focus group and interviews [CB, SB, KP]. The team developed and pilot tested a semi-structured interview guide. The guide included questions about views on identifying people in the community who are nearing the end of life, the risks and benefits of using a prognostication tool to identify people in the community who are at risk of death, the role of end-of-life risk prognostication to improve advanced care planning discussions and end-of-life care, reactions to having a tool like the prototype openly available on the internet, and impressions and feedback on the content and design of the tool. We told respondents that the research team had developed a web-based calculator to better identify people who are approaching end-of-life, with the aim of providing improved care at end-of-life. We indicated that their input would help us gain insights into the needs of patients and their families and caregivers and help us refine the tool. To ensure trustworthiness and credibility of the data, we took the following steps: all focus groups and interviews were audiotaped and transcribed verbatim by an experienced transcriptionist, independent and team analysis were conducted, field notes were generated during focus groups and interviews, and biases and beliefs which could influence the interpretation of the data were discussed and reflected upon.

2.4. Data analysis

We imported each focus group and interview transcript into qualitative data analysis software (NVivo, QSR International). We used a content analysis approach with pre-determined text analysis categories [25]. The initial coding template was developed by consensus of the investigators. Then, two investigators (CB and SB) independently reviewed and coded each transcript. The coders added new categories to accommodate response themes not included in the original template.

After initial coding, the two reviewing investigators met to review disagreements in the emerging coding, which were resolved by consensus. The coders then revised the coding template to include additional categories and remove unused categories. Next, (CB and SB) performed a second round of thematic coding using the revised master template.

To illustrate key concepts and ideas, the investigators identified exemplary quotes from within the data. The investigators continued collecting and analysing data until theoretical saturation was reached—that is, when no new information was being extracted.

3. Results

A total of 16 individuals, aged between 30 and 79 years, participated in this study. We conducted four one-on-one interviews: two with friend or family caregivers with personal lived experience or interest in palliative care and two with health care professionals. While five focus groups were scheduled (one with health care professionals, the remainder with friend or family caregivers) only two participants showed up for each of the friend or family caregiver sessions. Thus, we had one focus group with four health care professionals and the remaining eight friend or family caregivers participated in interviews with two individuals in each interview. The majority (63%) of participants were female. The duration of the focus group was 62 min and the interviews ranged from 21 to 108 min (mean = 59 min). The analysis led to five overarching themes: acceptability, communication, barriers to use, broadening the circle of care, and limitations of the tool and how it can be improved.

3.1. Acceptability

In general, participants viewed the use of an end-of-life predictive algorithm to identify people in the community who are nearing end-of-

life as acceptable. The risk information was viewed as a helpful resource for preparation, planning and provision of care for individuals.

3.1.1. Provision of comfort

There was also a sense that providing individuals and their families with personalized information facilitates emotional preparedness and could provide comfort with end-of-life care.

...would be beneficial, for sure, because it will give the providers more information. Yeah, and it would give more comfort to the family, that they are taking care of, if it's in the right way. [Interviewee 1, friend/family caregiver]

...my mother died, and my brother-in-law died, and the brother-in-law they had this marvellous doctor, and she told them exactly what to expect over the next months or whatever...you knew what to expect. And just because you know...it's certainly much easier to cope with it. [Paired interview 3, friend/family caregiver]

3.1.2. Preparation and planning

Participants also felt that risk prognosis (e.g., "how long") provides important information for friend or family caregivers and their preparation and planning. Having a better sense of when to take personal leave and to help with care or spending time together was seen as an important benefit of having an individualized risk estimate.

We've had many situations where somebody's been told by a doctor that's it's going to be eight months and they're holding on to that, and they pass within four weeks. So, maybe this [tool] gives them a more realistic approach... [Focus group, health care professional]

For me, this is the first and only time I've ever been given a [prediction]... when I asked the neurologist when she was first diagnosed... are we looking at one year, five years, ten years...and he couldn't tell me. And I said, well, I kinda need to know, because if it's one year to five years...I may put my studies off. [Paired interview 3, friend/family caregiver]

Identifying people in the community who are nearing the end of life earlier in their trajectory of decline was viewed as an important step for having conversations that prepare families and make it a more understandable process as well as providing an opportunity to put into place, plans for the end of life.

...my experience is that families are happy... to be able to talk about it, so that they aren't taken by surprise when things start to deteriorate. [Interviewee 2, health care professional]

I think sooner than later ... So okay, you don't want to hear that, but then you maybe make preparations what you need to do whether it's bank accounts, credit cards or things that you can do during that time [Interviewee 3, friend/family caregiver]

3.1.3. Risks and benefits

Despite participants' general views regarding acceptability, there was discordance on whether having a tool openly available in the community (i.e., on the internet) was the appropriate setting. Many participants were supportive of having the opportunity to access the final prototype tool. For those that expressed conflicting views, they felt that other individuals may not be able to cope with the risk information if it was distressing or they did not have support when accessing the information.

... I don't know how individuals, other than me, might receive, accept, deal with being offered information that's oriented towards end of life or forecasting or anticipating or indicating likelihoods... For myself, I would welcome it. From a public communications perspective, I can see where there's a risk... [Paired interview 1, friend/family caregiver]

For me, yes, and many of people in the same age, kind of same education, same socioeconomic, yes, they might like to know how much longer they, or loved ones, still have...But for my extended families, maybe for my wife, ...my parents...people back in the Middle East...they don't like to get faced right off with this bad news....So, yeah, it depends. [Interviewee 1, friend/family caregiver]

3.2. Communication

3.2.1. Facilitating communication

Participants felt that having access to personalized risk estimates could help clinicians, individuals and their families plan ahead and help to honour wishes for end-of-life care. The information was identified as being useful for engaging patients and their caregivers in goals of care conversations and, importantly, having those conversations earlier in the trajectory of decline.

I thought it was interesting that you started off the interview by talking about giving patients and caregivers some insight, but I think it's also really helpful to give insight to the clinician. And so, I think if anything, a tool is helpful as a conversation starter, that's how I view them in my mind. [Interviewee 2, health care professional]

3.2.2. Normalizing conversations around death

Moreover, participants felt that there is a need to normalize conversations around death, dying and bereavement and that current gaps in this area could be bridged by risk prognostic tools.

I think what really needs to happen is this needs to be brought to the forefront of people's minds. It needs to be something that people are willing to talk about, and society needs to move in that direction, easier said than done. And anything like this tool, it hopes for that to happen, cannot but be a good thing. [Paired interview 4, friend/family caregiver]

3.3. Barriers to use

There was discussion about the interpretation of a tool like our prototype for individuals with different, language, cultural, or educational backgrounds. Participants acknowledged that there are potential language or educational barriers to accurate completion of the tool and interpretation of the results, as well as different preferences for this information based on cultural beliefs and expectations around death and dying.

...people back in the Middle East...they don't like to get faced right off with this bad news. [Interviewee 1, friend/family caregiver]

With respect to the issue of having a tool like the prototype available in the community setting, some participants advocated for open access and patient autonomy while others felt it was more important to provide appropriate and supportive counsel in a shared care environment. Participants expressed concern for the readiness of people to be presented with end-of-life prognostication information. Participants also had concerns around what would be done after individuals are identified and the associated risks of being told their estimated survival time.

I personally see a far more upside than downside. But the downsides... would be dealing with individuals who might at least initially resist the message that please don't tell me. I don't want to hear that I'm ending my life ... they want to continue on in blissful ignorance... [Paired interview 1, friend/family caregiver]

It needs to be done, I think, this tool, in a very controlled setting and there could be sub data that medical professionals can look at...But I think it's an accident waiting to happen if you make this something that is available without control. [Paired interview 4, friend/family caregiver]

3.4. Broadening the circle of care

Participants felt that advance care planning should not be a single discussion, rather a conversation that is revisited to address changing care needs and preferences and includes a broader perspective than just family and the health team, for example, religious or community support groups. Participants felt earlier identification of declining health could facilitate both discussion of needs and broadening the circle of care to meet those needs.

I think everybody should be supported when they're dying and all through life...I mean because we're all in the same boat. We do support each other, you know, communities do and families do and your friends do or whatever community you belong to.... [Paired interview 2, friend/family caregiver]

....the doctor has to start the conversation I guess, if you have a diagnosis, but it's up to the, the family and the community to develop your own network... [Paired interview 3, friend/family caregiver]

3.5. Tool feedback

Overall, participants felt the prototype tool for use by patients and caregivers was informative and easy to use. They did provide constructive feedback regarding limitations and considerations of how prognostication should be performed. First, there was concern that the act of self-reporting and the subjectivity of interpreting some questions could lead to errors in the calculation.

it's gonna be as accurate as the people ...[who are] actually inputting it. [Paired interview 3, friend/family caregiver]

They felt the overall accessibility of the tool for different age groups and mobilities was a potential limitation. There was also concern that presenting results was challenging and required an understandable presentation of uncertainty. Participants suggested encouraging participants to seek the support of someone while using prognostic tools to help with the interpretation of results as well as providing emotional support if the information is distressing.

I would put in the option of...you may wish to consider completing this with your homecare worker, with your, with a family member, with your family doctor, who can help you. You know, before proceeding, like, again, because they could get this number at the end, and, and they're devastated. [Paired interview 3, friend/family caregiver]

Participants felt that risk prognostication could facilitate documented, coordinated care through direct sharing with family members and care providers or linkage to electronic medical records.

It can be linked to a [home care coordination service], it can be linked to palliative care, it can be linked so that everyone is on the same page. For example, when my mother was sick one doctor was saying no, no more IV fluids, she's going to die. Another one was saying something else. So one wanted the medical model and one wanted the palliative model. They couldn't agree and so we were stuck in no man's land... [Interviewee 4, friend/family caregiver]

4. Discussion and conclusion

4.1. Discussion

The results of this study suggest that the use of a tool to identify people in the community who may be nearing the end of life is generally acceptable and useful for facilitating advance care planning discussions. However, there was dissension on whether risk prognostication (end-of-life risk calculators) should be openly available to everyone in the community setting. For some, there was concern that the information

could be distressing and that it should not be done without the support of a healthcare professional. Others argued in support of patient and family autonomy and untethered access to the information.

Our study is the first we know of to examine patient and caregiver preferences for end-of-life prognostic information in the community setting. Similar to previous studies that have focused on identifying patients at risk of dying in primary care settings [26,27], participants supported the use of personalized risk tools to identify the risk of dying earlier in a trajectory of decline. Past research indicates that patients are open to discussing life expectancy with their physician and more so when life expectancy was shorter [28-31]. In contrast, participants in our study argued for early and ongoing discussions that are, ideally, informed by personalized risk estimates that facilitate open decision-making and recognise changing care needs and preferences. In cancer clinics, identification of high-risk cancer patients through machine learning algorithms increased serious illness conversations [32]. Our study is in keeping with previous studies indicating the motivations (e.g., preparing patients and their families, providing for emotional and spiritual needs, making medical and health-related decisions, and making the most of the time they have left) and barriers (e.g., uncertainty in prognostic estimates, concerns about upsetting the patient or getting negative reactions, and perceptions that patients may not be open to receiving prognostic information) for discussing end-of-life prognosis [28-31,33,34].

While the literature and our study suggest that most patients want to discuss their life expectancy, there are still people who may not want to receive this information. In addition to addressing uncertainty in the prognostic estimates, patient's preferences for receiving this information needs to be assessed. Having open access to risk prognostication may help to overcome barriers with respect to healthcare providers as gatekeepers to information that can inform the many decisions patients (and their family members) make at the end of life. Providing people with a prognostic estimate of their expected remaining months or years (life expectancy) can improve decisional capacity, enable advocacy for timely provision of supports needed at the end of life, and facilitate shared decision-making between patients and healthcare professionals. However, this access needs to be balanced and account for varying preferences for receiving this information and how they want to receive this information [35].

We had scheduled five focus groups, however four of the groups only had two participants attend. That stated, previous research has shown that dyadic interviews and focus groups produce similar results with respect to the breadth and depths of topics discussed [36,37]. Our sample included health care professionals and friend or family caregivers with personal lived experience or interest in palliative care. They were from one province in Canada and may not represent older adults elsewhere. Nonetheless, the findings reported here provide unique insights for supporting patients' and families' complex end-of-life decision-making needs. Supporting these needs is a key goal since quality decision-making leads to better outcomes for patients who often define 'a good death' as one in which these decision-making needs are supported sufficiently [38,39].

4.2. Innovation

This research explored patient and caregiver preferences for end-of-life prognostic information in the community, introducing the concept of accessible end-of-life risk calculators. Often, this type of risk information is either not available to patients and their families, or clinicians act as gatekeepers to the information. Providing older adults with a personalized estimate of their anticipated remaining months or years (life expectancy) can enhance their decisional capacity and facilitate shared decision-making with healthcare professionals. The tool introduced in this study, which was designed to predict mortality risk in older adults and be available in the community setting, is part of an active program of research around palliative care and continues to undergo

evaluation for the public's use. While this study provides an initial step to understanding critical factors for consideration, further research is needed to address how to communicate risk tool findings and explore additional benefits, harms, and barriers to implementation.

4.3. Conclusion

Our findings suggest there may be a role for accessible end-of-life risk calculators in the community setting. Understanding the implications of end-of-life identification in the community setting is critical to implementing prognostic algorithms in ways that facilitate sensitive and responsive identification, assessment, care planning, and improvement of quality of life. Community-based patient and caregiver studies are needed to assess risk communication of death at end-of-life and assess whether communicating risk improves quality of care.

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CRediT authorship contribution statement

Carol Bennett: Writing – review & editing, Writing – original draft, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Sarah Beach:** Writing – review & editing, Writing – original draft, Project administration, Formal analysis, Data curation. **Karen Pacheco:** Writing – review & editing, Project administration, Data curation. **Amy T. Hsu:** Writing – review & editing, Investigation, Conceptualization. **Peter Tanuseputro:** Writing – review & editing, Investigation, Funding acquisition, Conceptualization. **Douglas G. Manuel:** Writing – review & editing, Supervision, Investigation, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

References

- Costante A, Lawand C, Cheng C. Access to palliative care in Canada. *Healthc Q* 2019;21(4):10–2. <https://doi.org/10.12927/hcq.2019.25747>.
- Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* 2013;12:7. <https://doi.org/10.1186/1472-684X-12-7>.
- Fukui S, Yoshiuchi K, Fujita J, Sawai M, Watanabe M. Japanese people's preference for place of end-of-life care and death: a population-based nationwide survey. *J Pain Symptom Manage* 2011;42(6):882–92. <https://doi.org/10.1016/j.jpainsymman.2011.02.024>.
- Murtagh FEM, Bausewein C, Petkova H, Sleeman K.E., Dodd R.H., Gysels M., Johnston B., Murray S., Banerjee S., Shipman C., Hansford P., Wakefield D., Gomes B., Higginson I.J. Understanding the place of death for patients with non malignant conditions: a systematic review. Final Report. NIHR Service Delivery and Organisation programme; 2012.
- Gruneir A, Mor V, Weitzen S, Truchil R, Teno J, Roy J. Where people die: a multilevel approach to understanding influences on site of death in America. *Med Care Res Rev* 2007;64(4):351–78.
- Kalseth J, Halvorsen T. Relationship of place of death with care capacity and accessibility: a multilevel population study of system effects on place of death in Norway. *BMC Health Serv Res* 2020;20:1–12.
- Motiwala SS, Croxford R, Guerriere DN, Coyte PC. Predictors of place of death for seniors in Ontario: a population-based cohort analysis. *Canadian Journal on Aging/La Revue canadienne du vieillissement* 2006;25(4):363–71.
- Bekelman JE, et al. Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries. *JAMA* 2016;315(3):272–83. <https://doi.org/10.1001/jama.2015.18603>.
- Ontario Palliative Care Network. Tools to support earlier identification for palliative care. Ontario Palliative Care Network 2019 [Online]. Available: <https://www.ontariopalliativecarenetwork.ca/resources>.
- Hawley P. Barriers to access to palliative care. *Palliat Care* 2017;10. <https://doi.org/10.1177/1178224216688887>. 1178224216688887.
- Harrison N, Cavers D, Campbell C, Murray SA. Are UK primary care teams formally identifying patients for palliative care before they die? *Br J Gen Pract* 2012;62(598):e344–52. <https://doi.org/10.3399/bjgp12X641465>.
- Baker A, Leak P, Ritchie LD, Lee AJ, Fielding S. Anticipatory care planning and integration: a primary care pilot study aimed at reducing unplanned hospitalisation. *Br J Gen Pract* 2012;62(595):e113–20. <https://doi.org/10.3399/bjgp12X625175>.
- Thomas K, Noble B. Improving the delivery of palliative care in general practice: an evaluation of the first phase of the Gold Standards Framework. *Palliat Med* 2007; 21(1):49–53. <https://doi.org/10.1177/0269216306072501>.
- Sharp T, Moran E, Kuhn I, Barclay S. Do the elderly have a voice? Advance care planning discussions with frail and older individuals: a systematic literature review and narrative synthesis. *Br J Gen Pract* 2013;63(615):e657–68. <https://doi.org/10.3399/bjgp13X673667>.
- Abarshi EA, Ehteld MA, Van den Block L, Donker GA, Deliens L, Onwuteaka-Philipsen BD. Recognising patients who will die in the near future: a nationwide study via the Dutch sentinel Network of GPs. *Br J Gen Pract* 2011;61(587):e371–8. <https://doi.org/10.3399/bjgp11X578052>.
- Periyakoil VS, Neri E, Kraemer H. No easy talk: a mixed methods study of doctor reported barriers to conducting effective end-of-life conversations with diverse patients. *PLoS One* 2015;10(4):e0122321. <https://doi.org/10.1371/journal.pone.0122321>.
- Baxter R, Fromme EK, Sandgren A. Patient identification for serious illness conversations: a scoping review. *Int J Environ Res Public Health* 2022;19(7):4162. <https://doi.org/10.3390/ijerph19074162>.
- Greene SM, Tuzzio L, Cherkin D. A framework for making patient-centered care front and center. *Perm J* 2012;16(3):49–53. <https://doi.org/10.7812/TPP/12-025>.
- Griffin SJ, Kinmonth A-L, Veltman MWM, Gillard S, Grant J, Stewart M. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a systematic review of trials. *Ann Fam Med* 2004;2(6):595–608. <https://doi.org/10.1370/afm.142>.
- Rao JK, Anderson LA, Inui TS, Frankel RM. Communication interventions make a difference in conversations between physicians and patients: a systematic review of the evidence. *Med Care* 2007;45(4):340–9. <https://doi.org/10.1097/01.mlr.0000254516.04961.d5>.
- Hsu AT, et al. Algorithm for predicting death among older adults in the home care setting: study protocol for the Risk Evaluation for Support: Predictions for Elder-life in the Community Tool (RESPECT). *BMJ Open* 2016;6(12):e013666. <https://doi.org/10.1136/bmjopen-2016-013666>.
- Hsu AT, et al. Predicting death in home care users: derivation and validation of the risk evaluation for support: predictions for elder-life in the community tool (RESPECT). *CMAJ* 2021;193(26):E997–1005. <https://doi.org/10.1503/cmaj.200022>.
- Morgan DL. Focus group as qualitative research. Newbury Park, CA: Sage Publications; 1988.
- Nyumba TO, Wilson K, Derrick CJ, Mukherjee N. The use of focus group discussion methodology: insights from two decades of application in conservation. *Methods in Ecology and Evolution* 2018;9(1):20–32.
- Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15(9):1277–88. <https://doi.org/10.1177/1049732305276687>.
- Kendall C, Kotecha J, Martin M, Han H, Jorgensen M, Urquhart R. Patient and caregiver perspectives on early identification for advance care planning in primary healthcare settings. *BMC Fam Pract* 2020;21(1):136. <https://doi.org/10.1186/s12875-020-01206-w>.
- Urquhart R, et al. Stakeholders' views on identifying patients in primary care at risk of dying: a qualitative descriptive study using focus groups and interviews. *Br J Gen Pract* 2018;68(674):e612–20. <https://doi.org/10.3399/bjgp18X698345>.
- Ahalt C, Walter LC, Yourman L, Eng C, Pérez-Stable EJ, Smith AK. 'Knowing is better': preferences of diverse older adults for discussing prognosis. *J Gen Intern Med* 2012;27(5):568–75. <https://doi.org/10.1007/s11606-011-1933-0>.
- Kistler CE, Lewis CL, Amick HR, Bynum DL, Walter LC, Watson LC. Older adults' beliefs about physician-estimated life expectancy: a cross-sectional survey. *BMC Fam Pract* 2006;7:9. <https://doi.org/10.1186/1471-2296-7-9>.
- Fried TR, Bradley EH, O'Leary J. Prognosis communication in serious illness: perceptions of older patients, caregivers, and clinicians. *J Am Geriatr Soc* 2003;51(10):1398–403. <https://doi.org/10.1046/j.1532-5415.2003.51457.x>.
- Schoenborn NL, et al. Older adults' preferences for discussing long-term life expectancy: results from a national survey. *Ann Fam Med* 2018;16(6):530–7. <https://doi.org/10.1370/afm.2309>.
- Manz CR, et al. Long-term effect of machine learning-triggered behavioral nudges on serious illness conversations and end-of-life outcomes among patients with cancer: a randomized clinical trial. *JAMA Oncol* 2023;9(3):414–8.
- Wallace E, Murphy N. Discussing life expectancy with older patients: prediction and patient preferences. *Am Fam Physician* 2019;100(5):265–6.
- Bernard C, Tan A, Slaven M, Elston D, Heyland DK, Howard M. Exploring patient-reported barriers to advance care planning in family practice. *BMC Fam Pract* 2020;21(1):94. <https://doi.org/10.1186/s12875-020-01167-0>.
- Lewis ET, et al. How do patients with life-limiting illness and caregivers want end-of-life prognostic information delivered? A pilot study. *Healthcare (Basel)* 2021;9(7):784. <https://doi.org/10.3390/healthcare9070784>.
- Morgan DL, Ataie J, Carder P, Hoffman K. Introducing dyadic interviews as a method for collecting qualitative data. *Qual Health Res* 2013;23(9):1276–84.

- [37] Morgan DL, Eliot S, Lowe RA, Gorman P. Dyadic interviews as a tool for qualitative evaluation. *American Journal of Evaluation* 2016;37(1):109–17.
- [38] Malhotra C, Chan A, Do YK, Malhotra R, Goh C. Good end-of-life care: perspectives of middle-aged and older Singaporeans. *J Pain Symptom Manage* 2012;44(2): 252–63. <https://doi.org/10.1016/j.jpainsymman.2011.09.007>.
- [39] Steinhauer KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: observations of patients, families, and providers. *Ann Intern Med* 2000;132(10):825–32. <https://doi.org/10.7326/0003-4819-132-10-200005160-00011>.