Development and pilot testing of an electronic guide incorporating patient values and prognostic information in preparation for older people’s decision-making near the end of life.

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Abstract

Background

To develop an electronic resource, called Communicating Health Alternatives Tool (CHAT) that was compatible with hospital medical records software to facilitate preliminary patient-centered decision-making across health settings for frail older adults with progressive chronic disease.

Methods

Mixed methods including literature review; user-directed specifications; web-based interface development with authentication, authorisation, and secure cloud services; clinician and consumer co-design, iterative user testing; and developer integration of feedback.

Results

An internet-based conversation guide to facilitate clinician-led advance care planning was co-developed covering screening for short-term risk of death, patient values and preferences, and treatment choices for chronic kidney disease and dementia. Printed summary of such discussion could be used to begin the process in hospital or community health services. Clinicians, patients, and caregivers were generally accepting of its contents and format and supported its use in routine clinical practice.

Conclusion

CHAT is anticipated to enhance clinicians’ confidence in initiating these sensitive but important discussions with their older patients near end of life. CHAT is available to health services for implementation in effectiveness trials of patient-centered care to determine whether the interaction and documentation leads to formal decision-making, goal-concordant care, and subsequent reduction of unwanted treatments at the end of life.

Introduction

De-escalating medical procedures, prescriptions [1], and avoiding hospital transfers [2] near the end of life (EOL) in old age is relevant for multimorbid patients but complex for clinicians [3]. This is particularly true when patients or substitute decision-makers have poor understanding of disease trajectories and face dilemmas between personal values and treatment preferences [4]. Decision aids are valuable to improve consumer-clinician communication in the face of uncertainty and when there is no clear single management option [5]. Medical decision-making studies on chronic conditions highlight the need for clinicians to explore more values beyond treatment options into patients’ priorities, cultural context and life outlook [6]. There is moderate evidence that presenting patients with prognostic probabilities
improves their understanding of risk of overtreatment, and low-level evidence that decision aids align choices with patient values [7].

Recent reviews of decision aids for EOL [8, 9], however, revealed either a scarcity of tools for this context and or a lack of numeric prognostic information to assist patients and families in genuinely informed treatment decisions. More importantly, patients’ personal values and preferences for non-medical aspects of end-of-life care were not generally incorporated [8, 9]. Previous research on prognostic tools and preferences for disclosure [10, 11], have identified several aspects illustrating the complexity of decision-making near the EOL: full or partial prognostic disclosure may be a clinician’s duty but is not welcome by all patients and may best be delivered gradually over several encounters [12]. Many clinicians withhold bad news from families assuming lack of readiness[10], and patient willingness to engage in decision-making with clinicians varies with age, education and type of health conditions under examination [13]. The way choices are presented as positive or negative statements may unduly influence the direction of patient preferences [14]. Patient’s and family preferences for prognostic information also change as disease progresses and death approaches [15], but higher stability of decisions is observed among patients with severe progressive illness and those who have completed advance care directives [16].

Decision-making to administer, withhold or withdraw life-saving treatment needs to be a step-by-step consultation process. Recent calls for taking advantage of the benefits of digital information exchange to support elicitation of patient preference [17], supplement systematic evidence that current decision aids for end-of-life are still inadequate to meet patients’ needs both in terms of information shared and individual engagement [9]. Hence, our aim was to design a resource that would assist clinician’s (nurses or doctors) routine engagement in preliminary discussions with their patient and/or surrogate before formal advance care planning. The Communicating Health Alternatives Tool (CHAT app) is intended to enhance patient’s/surrogate’s understanding of the stage of illness, the risks and benefits of alternative treatments, knowledge of consequences of treatment limitations or withdrawal, and align preferences with values and goals of care. The ultimate purpose is the normalisation of the timely consultation with families of people with selected conditions (chronic kidney disease, chronic pulmonary obstructive disease, and dementia/cognitive impairment) to prevent potentially unwarranted or unwanted treatments.

**Objectives**

1. To develop an electronic, flexible resource compatible with hospital electronic medical records, that is applicable across several chronic conditions to facilitate preparation for shared decision-making among older people deemed to be in the last year of life.
2. To offer an acceptable combination of modules that incorporates quantitative prognosis and patient values during the clinical encounter across settings

**Methods**

**The process**
We used mixed methods including literature reviews, co-design, and acceptability testing interviews with potential users. While CHAT is not technically a decision aid but a preparatory conversation guide, our process was informed by internationally recognised quality criteria [18] where we searched the medical literature to identify treatment options, harms and benefits to provide qualitative information to clinicians. We limited the search for evidence of harms and benefits to randomized trials or controlled cohorts for treatment effectiveness of the three conditions as far as possible. We searched for qualitative studies or patient surveys to select items or questions that informed the patient values clarification module development. Questions were based on modified versions of other instruments as specified below in the results, in addition to newly developed questions based on the clinicians’ experience. The CHAT app uses language appropriate for a participant with an 8th grade reading level to facilitate understanding. The core development took place over 24 months (2018–2019) through ongoing consultation with a geriatric nurse, a clinical GP researcher and software engineers. Consultation included 12 clinicians (seven nurses in renal, geriatrics, intensive care, internal medicine specialties), a social worker, 3 general practitioners a respiratory physician, an academic pharmacist, attending a one-on-one demonstration to give their opinion on the different modules, and 13 older members of the public providing feedback which was incorporated in subsequent versions of the prototype (2020–2021).

The components and features

A set of demographic questions for both the patient and their surrogate (if appropriate) opens the e-documentation clinicians complete before the 3 modules of the interview (Fig. 1 also shows partial questions on the risk screening tool).

Screening for risk of death

This is an online version of the CriSTAL checklist, an acronym for Criteria for Screening and Triaging to Appropriate Alternative care [19]. The set of clinical factors flags patients with chronic illness who may be vulnerable to deterioration in the short term (Additional file 1). The print version of the CriSTAL checklist was adapted into the online CHAT application to facilitate the use for clinicians selecting those most likely to benefit from an end-of-life discussion. CHAT automatically calculates the risk score as clinicians click on the relevant risk factors, by adding one point per risk factor. Patients with a CriSTAL risk score of 6 or higher (out of a maximum 19 points) are considered at high risk of death based on the previously described validation for medical and surgical patient populations [20-22].

Personal values and preferences

A generic questionnaire built on modified versions of questions from other studies [23-26] is applied to all people with advanced comorbidities. This screenshot (Fig. 2) displays the layout of selected questions asked during the ‘Personal Values’ questionnaire and the importance rating for each. No scoring is calculated, as the answers are to inform subjective perceptions and can change from one visit to another. The side bar displays the patient summary and a quick navigation.

Chronic conditions
Disease-specific questions on preference for management options or decision-making were also modified from previously used themes or questions by others on chronic kidney disease (CKD) [27-30] and dementia/cognitive impairment [31, 32]. For dementia, some items were based on common complications that lead to hospital transfers [33] or intensive care admission [34]; a surrogate version of the questions was made available given the role families have in decision-making on place of care [35]. Both CKD and cognitive impairment were selected as the pilot health states due to frequency of cases in older age and convenience of testing in hospitals. No scoring system applies, only informative responses to guide clinicians. A module on chronic obstructive pulmonary disease (COPD) with detailed treatment choices was originally developed (Additional file 2 shows selected screenshots). However, feedback obtained from clinicians led to the exclusion of this module from CHAT as explained in the pilot testing section of this manuscript. The “Conditions” section is supplemented with a self-reported question “Today’s Health”: a slider scale from 0 to 100 where the patient can describe their perceived state of health (Fig. 3). As seen in this screenshot the ‘Today’s Health’ self-assessment uses only part of the screen, so clinicians can easily navigate back to the ‘Hospital’ view or the ‘Patient’ view or to other features of the conversation guide as indicated by the arrows. The green bar at the top displays the progress of the questionnaire so the clinician can see how many questions are left and adjust the speed of the consultation if required. The final purple button on the top right corner (grey navigation bar) is a link to the clinician’s profile, which is used by the system to track modifications on patient preferences including date stamps for auditing purposes.

If patients are fatigued or the interview needs to be suspended for the patient to undergo procedures, there are provisions to resume later, either the same day or at a subsequent appointment. This screenshot displaying the patient overview (Fig. 4) includes the patient identifiers, their latest CriSTAL score, their values as assessed by the Patient Values Questionnaire, and their chronic conditions.

**The My Choices summary**

This reproduces all patient/surrogate responses into a printable PDF file. Once the interview is completed, the clinician can cross-check, edit and save all changes before printing a copy for the patient or surrogate to take home or to share with their local general practitioner or specialist so a follow-up discussion and advance directive can be progressed.

**Technical Information**

**Authentication**

We secured the data entry function on the application with a password protected entry. Users of the app could only gain access if they were given a username and password by the research team. Secure access to the CHAT systems is achieved by implementation of the OpenID Connect [36], an interoperable authentication protocol. OpenID Connect allows for integrating third party identity providers to manage logins and identity in a privacy preserving secure manner. User provisioning and access is managed by Azure Active Directory (AAD), an enterprise grade identity service provider that allows single sign-on (SSO).
and multi-factor authentication capabilities. This approach allows for external identity providers, such as the New South Wales Health SSO service to be the authentication provider for the CHAT service.

**Authorization**

The authorization procedure is implemented using role-based access control (RBAC), which is governed by the roles exposed by the identity provider to the CHAT service, and the roles assigned to the user in the FHIR PractitionerRole object. The identity provider role is to discover whether a user is allowed to authenticate with the service, and the PractitionerRole authorizes the user's visibility to clinical records, and product features. The PractitionerRole is an assigned relationship between the health service and the petitioner, allowing a clinician to have different levels of access per health service.

User provisioning is handled by the research team, first by inviting the user to the configured Identity Provider, then assigning the user the correct role that allows them to authenticate with the CHAT Service, clinician, or administrator. The second step in provisioning a user is to create a Practitioner and PractitionerRole in the CHAT service, this is achieved by using the CHAT Portal's user interface and has the option of assigning a PractitionerRole of Researcher or Nurse to the new user backend.

**CHAT Back-end / FHIR server**

The CHAT backend service is built upon the HL7 Fast Healthcare Interoperability Resources (FHIR) specification [37], to achieve interoperability and data mobility with existing health care services. We used an open source FHIR project developed by Microsoft to ensure compliance with the specification. The back-end leverages Azure cloud services to achieve government regulation compliance and strong data security for maintaining and storing personal health information which is rated as highly sensitive by the Australian Signal Directorate and relevant government bodies (Additional file 3).

To achieve some of the design goals of the CHAT project it was necessary to modify the standard FHIR specification. The FHIR specification has a mechanism for modifications, called extensions, allowing the ability to modify resources and elements, without breaking adherence to the specification.

For the CriSTAL questionnaire, a new extension was developed to tag questions with scoring rules and values. The new extension allowed for dynamic changes to the scoring calculation without having to modify code in the service.

A standard questionnaire extension was used called questionnaire-item-control, this extension allows for modifying the standard format of a question to be displayed differently depending on the value specified in the extension, such as, displaying a slider for a single choice question. Other extensions were used to express exclusivity on a multichoice questions, display a supporting link and hiding computed values.

**CHAT Front-end**
CHAT is designed as a web-based interface to be used from computers. A future extension is planned for a mobile phone app version. The CHAT front-end is single page application developed and implemented using React JS, Redux for state management, and Redux Final Form for form development. It allows the practitioner to register patients, fill out various questionnaires where certain selections activate other modules (e.g. CKD or cognitive impairment/dementia) and when all necessary questionnaires are completed, export the questionnaires as a printable PDF format. This may now be kept on record, with a printed copy given to the patient/surrogate. Fig. 5 shows the relationship between the different components indicating the clinician’s ability to move between screens to edit various sections during the clinical encounter and the final printable My Choices PDF.

A demonstration video summarising the basic features can be accessed in OSF (https://osf.io/6v7nb/).

Results

Clinicians were asked for usability and acceptability feedback at the end of the interview, using a standard form [38] refined by the clinician authors through a series of iterative internal consultations (Additional files 4a and 4b). No questionnaire validation was attempted, and one clinician gave qualitative feedback without using the standard form.

The original COPD module

It included a button with bullet point script on alternatives, and a pop-up image of a table containing comprehensive evidence-based details of prognostic factors, harms and benefits of the various treatments derived from our literature review (by BMR, EL and MC). The first round of feedback on this module strongly indicated doctors rejected that level of information density during a patient encounter. Negative reaction was clear to the appropriateness of generalising treatment options for a condition that -in their experience- required a personalised plan where every patient was different, and some options would not be offered in certain settings. As a result, the treatment options and prognostic details were removed altogether. CHAT interviews for COPD patients in future will include the risk of death and patient values module only.

The CKD module

It was designed with a table of prognostic factors derived from the literature review (EK, EL) for different management options and questions on satisfaction with current management which led to skips or activation of further questionnaire sections. It was later redesigned, as feedback from renal nurses on the generic and evidence-based tables on treatment alternatives suggested the inclusion of routine symptom checklist, images, and infographics already in use in routine dialysis care. These were added as an “additional information” button where nurses can refresh knowledge on evidence for alternatives and read scripted information on what treatment not to offer older patients in end-stage CKD (e.g. transplant) if asked.
The cognitive impairment/dementia module

This module applies to patients with cognitive impairment who have mental capacity, or their surrogates of people with dementia. It focuses on preferred place of treatment, and the level of intervention intensity in the case of future critical illness, such as hospital or ICU admission, intravenous medications or life support. There were several favourable comments on what participants liked about the dementia questionnaire with participants stating it was ‘extremely satisfying’, ‘normalised dementia diagnosis’, ‘reiterated what and how I felt with regard to dementia’ and one participant commenting ‘This is the first time I’ve ever spoken in depth about my dad’s dementia. It’s taken a lot of pressure off my chest’. One participant suggested families should receive more information about dementia if the CHAT app were to be developed into a decision tool. No participants had further comments on how a dementia module could be improved.

Overall Piloting and Usability Testing

Our participants’ inclusion criteria were a) doctors or nurses from relevant specialties – geriatric medicine, respiratory medicine, internal medicine, intensive care, social work. b) older people aged 60+ years with multiple comorbidities, and c) informal caregivers. After obtaining written consent from patients and family members who assisted in piloting CHAT app, nurses administered the CHAT to 13 older volunteer participants from our Consumer Advisory group and older patients either in the community, at a local hospital, or at the university premises. The pilot testing was endorsed by the University of New South Wales Health, Medical, Community and Social Ethical Review Panel (approval HC16159).

Overall feedback indicated user-friendliness (Fig. 6) and nurses trialling the CHAT on different patients and informal caregivers concluded that the duration (between 30-45minutes) of the testing consultation was long but acceptable given the topic for a non-emergency service.

The conversation guide components and additional information gave nurses confidence to answer patient questions during the session. Multiple requests for wording simplification, question flow, font size/colour changes, clarification on the use of Likert scales, and layout improvements were recommended and trialled at the various rounds.

All patients with chronic conditions and/or informal caregivers (of patients with dementia) reported that the duration of the consultation was just right, and no participant reported the information to be upsetting. For people over the age of 80 our interviewers noticed the interview length led to some respondent fatigue despite their interest in the testing. All reported that CHAT was completely balanced (i.e. not trying to persuade them to one treatment choice or another). Caregivers were satisfied and some relieved with the questionnaire content Only two patients reported wanting more information during the consultation and all but one patient found the information presented as unclear. More than half of the participants reported that CHAT was very helpful in deciding about treatments for their (or their surrogates’) health condition.
Performance of the CriSTAL scoring and questionnaire sections to be skipped were repeatedly tested for error checks, autofill and other questions relocated for logical conversation flow. User feedback was communicated to the software engineers on a periodic basis and changes in logic and language incorporated following several rounds of feedback on the different modules between 2019 and 2021.

Discussion

At the time of CHAT planning, the literature did not offer comprehensive electronic resources for the purpose of end-of-life decision preparation. The CHAT development including consumer co-design and internal capacity building has resulted in a simple guide to encourage clinicians to document patient end-of-life preferences early, and to motivate patients and families to commence the stepwise decision-making process.

Increasing evidence suggests that discussions on terminal care preferences are delayed or omitted by clinicians [39]. End-of life conversations including those nurse-led discussions, can enhance patient autonomy [40] or engagement in their own health management [41], and that patient subgroups using decision aids are less inclined to request aggressive treatments towards the EOL [42]. To address this gap, our goal was to enable an early and standard conversation flow by a range of clinicians including non-doctors in preparation for the difficult decision time. A mixed methods approach was taken with literature reviews to build the evidence, qualitative consultation with older members of the public, and field testing with clinician end-users. Engineers, clinicians, and researchers translated the needs into a web-based interface that enabled the production of a statement of wishes at the end of conversations.

The CHAT app was designed as a combination of an informative risk of death tool for clinicians, a patient values clarification statement alongside evidence summaries and prognostic knowledge awareness, question prompt list, and evidence-based description of the options, with associated benefits and harms of treatment options presented for specific health conditions if patients or surrogates wanted to know more [43]. Following clinician feedback, neutral question language was chosen to prevent biasing response choices regardless of interviewer uncertainty [44] and complex numeric information removed. Our process incorporated pragmatic aspects proposed in a recent conceptual framework for ageing and decision making [45]: involving aged patients recognising their cognitive decline and the complexity of their health experience, aiming for joint decisions with clinicians and informal caregivers, and targeting special outcomes for this stage in their lives. Our approach also follows recent recommendations to promote personal health choices using digital support for values clarification [17].

Despite the knowledge that decision aids contribute evidence to prevent variation in practice [5], minimise family conflict[8], and avoid clinicians biases in treatment recommendations during goals of care discussions [46], clinicians consulted during our pilot test were disinclined to use the comprehensive numeric prognostic information in routine care, while nurses found the quantitative prognostic information useful only if they could access it before the interview with patients. Doctors were confident in being up-to-date on clinical practice that did not require that level of detailed quantitative
explanation for them or to patients. It might not be feasible in practice for CHAT to be updated yearly for all emerging treatments in plain English for older patients, so it is reassuring that clinicians feel confident about their continuing education. Doctors perceived that the tables were too complex and could confuse patients and lead to cognitive overload. In the past this has been flagged by others as a risk for provider-introduced bias and care disparities among the less educated minority groups [47]. Doctors and nurses involved in our pilot testing were more motivated to use the CriSTAL risk of death tool and values clarifications modules. Patients and surrogates also welcomed the values clarification module as an ice-breaker in preparation for future discussions and decisions, but an effectiveness trial [48] will be needed to determine its impact on and consistency with the final decision.

Older members of the public rated the questions as clear and important, albeit some who had not considered the issues before found them a little confronting. No user found the contents upsetting but this could have been due to the type of volunteers we recruited, who were generally keen to discuss terminal illness issues, the role of clinicians, and assist in improving end-of-life care. Momentum is building with others in Canada successfully introducing hypothetical scenarios for older frail patients in non-trial conditions using the Clinical Frailty Scale and discussions on future care in the face of multimorbidity and deteriorating health [49] . In the past year one trial has also proposed a preparation support for future critical illness [50].

While the question is not if but when to hold preparation for death discussions, debate persists on how to approach these conversations with terminal patients. Some propose to “just ask” hospitalised patients directly in case of acute illness [51], while others favour a stepwise approach [52, 53] with a road map before crisis time [54]. The where is also a critical question since the pressures of the Emergency Department—our initial target setting, is not the most suitable environment for a long private conversation. GPs may be willing to start the conversation but are time-poor [55] and may not feel fully equipped with the answers for complex cases. Future iterations of the CHAT app can investigate whether nurses are the best placed to use the app in the initial stages, and whether the app can bridge this knowledge gap by allowing better collaboration with the GP and the specialist in the patient care trajectory.

**Strengths and limitations**

This development process was designed as a capacity building initiative with the contributions of Master’s and post-doctoral students. While this translated in delays, it also ensured we kept the skills in-house for future adaptations to other chronic conditions or health settings. The intermittent contributions of patient members of the target group effectively meant that co-design ensured a relevant and appropriate set of questions and interview duration. The CHAT app was planned in a simple language to facilitate patient understanding and designed to be used by not only by doctors but also other clinicians, who often play the valuable role of informants and mediators in decision-making [56]. CHAT did not include video [57] or other visual aids as our concurrent investigation on visual preferences for prognostic information on a separate group of older people revealed that the preferred format was the
traditional verbal delivery by the clinician with a written summary, rather than pictures, video, infographics or statistical tables [11]. Other limitations that could be addressed in the future include language barriers and future refinements to ensure the culturally appropriateness of conversation guides for diverse populations, who may approach the topic of death in different ways, just as they differ in their preferences for other healthcare delivery [58]. The combination of capacity building and the intermittent disruption by staff turnovers and COVID-19 lockdowns delayed the completion of field testing with patients.

**Practice Implications**

We intend to conduct an effectiveness randomised controlled trial of the impact of the CHAT structured, clinician-guided end-of-life discussion on both the likelihood of opting for non-invasive management among older people and/or their substitute decision-makers, and satisfaction with the process. Beneficiaries in hospital wards, residential aged care and general practice will be a broad, multimorbid older frail group rather than a disease-specific target group, as recently recommended in the validation of a values clarification tool for people with serious illness [59].

In conclusion, a range of initiatives have attempted to address the delayed discussion on the sensitive plan for end-of-life care in routine practice. Our proposed CHAT app version 1.0 aims to fill this gap of incorporating risk of death screening, patient values, increasing awareness of irreversible disease trajectories among patients, treatment options, and gradually preparing patients and families for a normalisation of the prognostic conversation and future formalisation of care directives. The easy accessibility to CHAT through a secure web-interface, its compatibility with the electronic medical record, and simplicity of information on two common chronic conditions are a first step in the right direction to enhance awareness among clinicians of the potential for unnecessary treatments when difficult conversations are not initiated. We offer technical support for this web-based product and hope to introduce it free of charge to health services interested in undertaking wide testing of its feasibility and effectiveness in a randomised controlled trial.

**Abbreviations**

CHAT
Communicating Health Alternatives Tool
CKD
Chronic kidney disease
CriSTAL
Criteria for Screening and Triaging to Appropriate alternative care
COPD
Chronic obstructive pulmonary disease
EOL
end of life
FHIR
Fast Healthcare Interoperability Resources
RBAC
role-based access control, SSO:single sign-on.

Declarations

Acknowledgments

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Authors’ contributions

Conceptualisation: MC, EL, JH, AB, CF, HA; funding acquisition: MC, EL, HA, NL; contextual literature search: EK, JT, GI, BMR, EL, MC; Development: JH, JJL, MC, EL, ABB, GI, CF, PGB; Supervision: NL, MC, JH; pilot testing: EL, MC, SR, LB, MT; feedback: JH, NL, EL, GI, SR, LB, ABB, HA, MT, PGB; manuscript production: MC, ABB, EL, PB; manuscript revision: all authors.

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Availability of data and materials

The dataset(s) supporting the conclusions of this article is(are) included within the article and its additional file(s).

Ethics approval and consent to participate

Data collection and contact with patients and clinicians was approved by the University of New South Wales Health, Medical, Community and Social Ethics Review Panel [approval HC16159]. Written consent to participate was obtained from all contributors to the field testing.

Consent for publication

Not applicable

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.
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Figure 1

Demographics module and risk of death.
Figure 2

Selected questions of the Personal Values module.
Figure 3

Features of the Chronic Conditions module.
Figure 4
Overview of all CHAT modules.

Figure 5
CHAT app front-end and screen sequence.
Figure 6

Clinician's reactions to CHAT prototype.

Supplementary Files

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- AdditionalFiles14.docx