**Patient and family priorities at the end-of-life: a qualitative consultation.**

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**Abstract** *(word limit 200)*

Objectives: As older adults approach the end-of-life (EOL) many are faced with complex decisions whether to use medical advances to prolong life. Limited information exists on the priorities of older adults at the EOL. This study aimed to explore the experiences and perceptions of factors that are viewed as priorities to ensure quality EOL care.

Method: Three focus group discussions (n=18) and six in-depth interviews with older adults suffering from either a terminal condition and/or caregivers in NSW, Australia. Thematic content analysis was conducted. .

Results: Seven major themes were identified: quality as a priority, sense of control, life on hold, need for health system support, being at home, talking about death and competent and caring health professionals. An underpinning priority throughout the seven themes was knowing and adhering to patient’s wishes.

Conclusion: Our study highlights that to better adhere to EOL patient’s wishes a reorganization of care is required. The readiness of the health system to cater for this expectation is questionable as real choices may not be available out of acute hospitals. With an aging population, a reorganization of care which influences the way we manage terminal patients is required.

**Keywords**: end-of-life; care priorities; older adults; qualitative study

**Introduction**

Increased use of emergency services and hospitalisations among older people who are dying[1](#_ENREF_1) often includes intensive procedures[2](#_ENREF_2) that can prolong suffering and are too late to be of benefit.[3](#_ENREF_3),[4](#_ENREF_4) Evidence that patients or families have been consulted regarding their preferences for future care and how this consultation has occurred is limited but critical to the provision of appropriate end-of-life (EOL) care.[5](#_ENREF_5)

Older patients and their families are usually provided with information about hospital-based treatment options[6](#_ENREF_6),[7](#_ENREF_7) regardless of whether they wish to spend their last days in an acute care hospital.[8](#_ENREF_8),[9](#_ENREF_9) You et al[10](#_ENREF_10) report that patients and families lack understanding of the implications of life-sustaining treatments, with Wilmott and colleagues[11](#_ENREF_11) finding that a patient's substitute decision makers do not always act in the patient’s best interest. As a result a patient’s wishes may not be known or honoured. Additional factors that can further complicate EOL decision-making are: the low public awareness[12](#_ENREF_12); cultural values affecting care preferences at the EOL; [13](#_ENREF_13),[14](#_ENREF_14) family denial of the patient's prognosis;[15](#_ENREF_15) potential cognitive impairment in old age;[16](#_ENREF_16) conflicting family pressures;[17](#_ENREF_17),[18](#_ENREF_18) and the level of a doctor’s professional expertise in communicating a terminal prognosis sensitively.[19](#_ENREF_19)

Health professionals providing quality EOL care across all health services must have an understanding of the family and patient’s perception of what is appropriate and contributes to high quality care, and what constitutes a “good death”.[20-22](#_ENREF_20) This information is necessary to fully inform clinical and other support staff providing EOL health services. Existing data that demonstrates the use of medically inappropriate treatments at the end-of-life and the importance of engaging in advance care planning may assist to inform more honest end-of-life discussion.[23](#_ENREF_23),[24](#_ENREF_24)

Research to date on EOL care has been predominantly conducted in the cancer realm[25](#_ENREF_25) and although informative does not take into consideration the EOL trajectory of other terminal conditions, with more people dying from diseases of aging and living longer with chronic conditions.[26](#_ENREF_26) Despite the Australian government recognizing the importance of providing high quality EOL care[27](#_ENREF_27) and developing guiding principles and essential elements for the provision of safe and high quality EOL care [28](#_ENREF_28) a recent Australian based population cohort found that only fourteen percent of non-cancer patients in the last year of life received specialist palliative care compared to more than two-thirds of cancer decedents.[29](#_ENREF_29)

This study sought to understand older adults at the EOL and their caregivers on EOL perspectives; the perceived appropriateness of current EOL; and their perspectives regarding the impact of EOL care on the patient’s quality of life and family dynamics; perspectives on EOL decisions; the perceived appropriateness of current care pathways; and their perspectives regarding ethical dilemmas in EOL care.

***Objectives***

1. Define current priorities in EOL care for terminal patients, their caregivers
2. Elucidate the main components of ‘quality’ at EOL
3. Explore the perceived impact of treatment for terminal illness on the individual and their caregivers
4. Identify the important health service factors for quality EOL care

**Methods**

***Sample frame - Consumer EOL advisory group***

The sample frame was members of the UNSW consumer EOL advisory group, established to identify priority concerns to inform on the public perspective of our research projects. Between November 2015 -March 2016, a call for older adults/carers of older adults to participate in the UNSW consumer EOL advisory group was undertaken through advertisements in academic and hospital/nursing home networks and by word of mouth. The UNSW consumer EOL advisory group were Membership eligibilityincluded: direct experience of health services for advanced chronic illness including terminal care either for a relative, friend or themselves; or experience in providing physical and social aspects of care for frail terminal older adults and/or their relatives towards their EOL; or commitment to the concept of improving the EOL experience for themselves or others. Those who were interested in becoming a member of the consumer advisor group responded via email and/or telephone. A total of 37 people, mostly aged over 60 years joined the consumer EOL advisory group. However, it also included younger adults (30-49 years) who informally cared for older people.

***Sample and data collection***

All of the consumer EOL advisory group members were invited to participate in this study with a total of 24 agreeing to participate. 90-minute focus group discussions (FGD) were conducted on the same day in April 2016 and 90-minute in-depth interviews (IDI) were undertaken during the month of June 2016. IDI were necessary to capture perspectives of those who were unable to participate in FGD due to geographical difficulty or poor health. Members of the study team developed the FGD guide which included four main topics EOL care, quality of life factors, family impact and healthcare provision (Appendix 1). The IDI guide that reflected the FGD topic was also generated for those who lived away from the city where the study was conducted or for those volunteers who were too ill to attend the focus groups. Written consent was obtained from each participant. Study team members with either a psychology (RH) or nursing background (EL, LH), who were trained in qualitative methods, facilitated the three 60-minute FGDs in a private meeting room on a University campus. The facilitator guided participants through each of the topics. The FGDs were audio-recorded and written notes were also taken by the team members. One team member (EL) was present for all FGDs and listened to the transcripts from all FGDs to ensure consistency. EL conducted all IDI using the agreed guide.

***Data analysis***

The audio-recorded qualitative data were transcribed verbatim and managed using NVivo software (version 11) QSR, International Pty Melbourne, Victoria, Australia).

Thematic content analysis was used to elicit themes from participants regarding whether quality or length of life was most valued, attributes of good quality living, the effect of EOL involvement on caregivers and their experiences and expectations of health professionals providing this care. Two team members (RH, EL) independently conducted the thematic analysis [30](#_ENREF_30) repeatedly reading the transcripts, labelling consistent or divergent issues arising, and independently deriving key themes. These researchers held iterative discussions and reflections [31](#_ENREF_31) then refined the themes and labelled and merged agreed groups of themes into categories. A third researcher (LH) who observed the FGD checked the categories and themes for face validity.

**Results**

Twenty four ethnically diverse (15 born in Australia, 10 born in Mediterranean, Eastern European, South Asian, Middle Eastern and American countries), predominately aged 60 years older (20), participants (17 women and 7 men) attended the FGDs (18) or had an IDI (6) and almost half (14) were informal caregivers of people facing EOL decisions and five subjects lived in rural/regional Australia. Ten participants suffered from a chronic progressive or life limiting illness themselves - Chronic Kidney Disease with multiple transplants (1); Advanced Parkinson's Disease (1); Breast Cancer (1); Heart failure (2); COPD and inoperable brain tumour (1); Motor Neuron Disease (1); Organic dementia (1); frailty (2). The other 14 subjects were past or current caregivers for family members who had suffered a terminal condition.

Seven themes emerged from the analysis of the FGD and the IDI transcripts: *quality as a priority, sense of control, life on hold, need for health system support, being at home, talking about death and competent and caring health professionals*. An underpinning priority that fed through the six themes was knowing and adhering to *what the patient wants*. Figure 1 illustrates these themes and the factors within each theme that were assessed by the participants as being a priority for optimal EOL care. Each theme is also described below with supporting quotes.

<Figure 1 here> **Themes on patient and family priorities at the EOL**

***Quality as a priority***

Participants across the FGD and IDI agreed that a good quality of life was the most important consideration in EOL care; prolonging an uncomfortable existence was not the goal.

*‘Well the specialist and everybody said that's it, there's no quality of life, they're not going to recover from the illness, they can't so it's just waiting…’* (Female, Caregiver)

*'I don’t want to prolong my life at all. As long as I’m independent I’m quite happy but if I become reliant on other people I do not wish to live under the circumstance.'*

(Male, COPD and inoperable brain tumour)

'*I have no interest in the quantity of my life; I have every interest in the quality.'* (Female, Terminally ill, Organic dementia)

However, many participants suggested that prolonging life is important when there continues to be hope for treatment and when associated with being younger.

*‘A lot of people are living with the hope that they will be treated. So prolonging the life could be a valid point…especially with the new interventions.’* (Male, Caregiver)

*‘So in prolonging life was there also quality of life during that prolonging? For me, that's a major question’* (Female, Caregiver)

Participants also suggested that when making assessments and decisions about whether prolonging life is beneficial to the patient, understanding and adhering to the patient’s wishes was critical. Seeking to know patients’ wishes and adherence to advanced care directives were seen as an essential part of personalised care.

*‘A year before that she had…gone to the solicitor and written that she didn't want any pharmaceutical, medical or surgical intervention. I came in the next day and she was being pumped full of antibiotics’* (Female, Caregiver)

*‘Part of the medical system is this giving of medications, keeping the medications on, ignoring directives like ‘Don't Resuscitate’ ’* (Female, Caregiver)

***Sense of control***

Participants expressed difficulty in defining quality of life factors but converged on the notion that a good quality of life is when an individual has control and can meet their own personal standards and expectations. These standards and expectations were perceived as dynamic throughout life and at the EOL as physical and cognitive abilities deteriorate.

*‘So my quality of life description is - and it's very personal - up until I was 80 was to make 80 and it was going to give me the quality of life I wanted. After I turned 80 and then I'd had a fall this week…’* (Male, Advanced Parkinson's Disease)

*'Quality of life when I think about myself is about having a say in my life and being able to have some self-agency and to be able to have a say in what happens to me and to be able to have some capacity to direct things.'* (Female, Motor Neuron Disease)

Good quality of life was defined by participants as being able to do the things a person enjoys and maintaining their sense of self through these activities, or as the patient’s ability to achieve their aspirations whatever those may be.

*‘He was a passionate music lover and that had been one of his great loves. So right up in fact to the moment that he was dying he was listening to his favourite.’ (*Female, Caregiver*)*

Loss of control was consistently identified by the participants as a loss of quality of life and linked to a perceived loss of dignity. Caregiver participants experienced distress at watching a loved one losing control of their thoughts and actions.

*‘So by this time she gets to the nursing home, she's faecally incontinent; she's urinary incontinent; had to hoist her up on that thing to hose her down; you know absolutely awful.’* (Female, Caregiver)

*‘For someone with a mental disease, brain degeneration, as my husband has, who has no quality of life…everything has to be done for him… but we have to wait until there is another medical disease before he can be placed into palliative care.’* (Female, Caregiver)

***Putting family life on hold***

Caregiver participants described the impact of their loved one’s life-limiting illness as putting their life on hold to care for another, making financial, career and personal compromises in order to do this. All of the participants who had experienced caring for a loved one at the EOL discussed common features of this caring role.

*‘In the last year of my mother's life I had three fairly young children. I used to go at 6:30 am or 6:00 am to visit her so I could get home in time to take the kids to school. I was also at full time university…I did it somehow but it certainly impacted.’* (Female, Caregiver)

*‘It was enormously stressful because this is over a period of six years. My sister was working, I wasn't, but our parents lived separate from both of us so we had lot of the car driving, a lot of expense.’* (Female, Caregiver)

‘Juggling’ family life and caring responsibilities was a challenge, with many participants highlighting the uneven distribution of caring responsibilities between family members. In some cases, this raised tensions between family members, and in some cases led to the process of agreeing roles.

*‘My sister and I are very different, but we negotiated the care really, really well, because we both acknowledged what our strengths were and we did them.’* (Female, Caregiver)

*‘I guess as the person who takes on the most of the caring role you sometimes feel a bit abandoned by the rest of your family because it’s just presumed you will be there…’* (Female, Caregiver)

Carer participants described EOL care as emotionally difficult. Feelings of guilt, denial, distress and sadness were noted in addition to the physical and logistical challenges of caring for a loved one. Although caregiver participants sought to adhere to patients’ preferences regarding not prolonging their life, conflicting feelings occurred as participant caregivers also did not want to lose their loved one.

*‘I think I've had both those feelings; wanting them to hang around, but also wishing them a speedy goodbye for their sake.’* (Female, Caregiver)

***Need for health system support***

Caregiver participants stated that they required support in navigating the complex health system and learning to be a carer for the first time.

*‘I would like to see them (caregivers) being formally supported in some way….supports people through what they're learning, because you're learning stuff. You know it's like this whole new world.’* (Female, Caregiver)

*'I'd really like to see something in institutions where there was somebody who would help coordinate some kind of care amongst the people who care about this person'* (Female, Caregiver)

***Being at home (at EOL)***

Participants agreed that it was generally preferable to stay at home for as long as possible. Consultation with health providers and choice regarding the location of their treatment and care was identified as important.

*‘Dad was in palliative care and basically he didn't want to be there at all…one day mum went in and he said take me home….So he was home for a week and then passed away at home, but at least he met his wishes.’* (Male, Caregiver)

*'The hospital is an alternative, I would never say the home is an alternative… the hospital has to be the last place on earth in any country that you would need to go simply to die'.* (Female, Caregiver)

Yet caregiver participants identified cases in which this was not possible, such as when the person or their caregiver did not have the ability to provide the care required. In these cases, carer participants often reported a need for greater support from other social or community based-services to facilitate care at home.

*‘We knew we couldn't deal with it at home ourselves, but had there been other kinds of care, that would have been perfect. He would have still been in his own garden and done his own little pottering around the place as he always did’* (Female, Caregiver)

*'She couldn't cope at home and she's gone into an old age home and that's much better all-round than trying to cope at home'.* (Male, Caregiver)

***Talking about death***

The importance of knowing and acting on patients’ wishes regarding their EOL care was consistently noted. Openness about impending death, honesty and transparency between patients, their family and healthcare providers were viewed as important in ensuring appropriate, patient-centred, EOL care.

Yet participants highlighted the difficulty of talking about death at every level; between patients, family, health professionals and at a societal level.

*‘I think it's a bit the same as the culture, the kind of health culture, there's not a kind of a literacy in our community, in our society around death. It's not easily spoken about.’* (Female, Caregiver)

Caregiver participants often described the reluctance of their loved one to talk about their deterioration and what they wanted. Some identified this as culturally influenced but the participants generally agreed that discussions about death were uncommon across cultures.

*‘The doctor brought up the question of the directive to see whether to switch off the life support machine just in case … but she hated to talk about that. Plus with our cultural background they don't like to talk about it.’* (Male, Caregiver)

*‘She was actually very grateful for the way that the doctor spoke to her… and I think all of us that were in that chemo room with all the other women, we recognised that in him, that that's the way he operated and I think everybody appreciated that kind of honesty.’* (Female, Caregiver)

***Competent and caring health professionals***

Participants identified that a consultative, patient-centred care approach was critical. They stated that health professionals who provided compassionate, respectful care, ensured patient dignity and were competent were described as playing a significant role in providing comfortable care for patients and supporting their caregivers.

*'…Good relationships with the primary health team is what I think is absolutely essential…. …A good relationship someone who understands you and understands the family and who will work with other professionals, you know for preference is like a GP practice that utilises some nurses and allied health professionals as necessary and who will work with them and work with the families'.* (Female, Motor Neuron Disease)

*‘She came in to find her with an oxygen mask on and we had said no resuscitation. The doctor said something like she won't need that anymore and walked out the door. That was how my sister discovered mum had died.’* (Female, Caregiver)

'*It's when people are at the end-of-life there will be a lot of trainees in the health care system trying to assess/learn and maybe if that could be minimised.…and everyone would like to assess fluid retention they might have a go. It's uncomfortable for the patient who's struggling with end-of-life.’* (Male, Heart Failure)

**Discussion**

The priorities for high quality EOL care identified by the study participants, who were mainly caregivers of people who have had or are experiencing terminal conditions, were: quality as a priority, sense of control, how to manage life on hold, need for health system support being able to remain at home if possible, talking about death to know what patient wishes are, and having competent and caring health professionals. In particular, our data highlight the importance of knowing and adhering to patient’s wishes (if known) when providing EOL care.

Our findings reinforce the call for patient-centred care, i.e. healthcare that is responsive to the preferences, needs and values of each patient [32](#_ENREF_32) regardless of whether the goals of care are curative and interventional or focused on a palliative approach. Our findings also support the need to include consumer voices in facilitating health service improvement. [33](#_ENREF_33)

According to other research with terminal patients and their caregivers priorities for high quality EOL care have included: the need for professional communication, honest consultation on preferences, respect for patient dignity, support in navigating the health system, control in decision-making, consideration of the burden on family life, and access to skilled health practitioners who are good communicators.[34-37](#_ENREF_34) A systematic review in 2015 of quantitative studies in Canada, US and the UK aiming to find the most important aspects of inpatient EOL care of palliative patients and their family found similar results to our study in Australia.[23](#_ENREF_23) Since that review we identified two relevant qualitative studies one in the with caregivers of people with dementia [38](#_ENREF_38)and one in Australia in 2017[39](#_ENREF_39) with caregivers of people with advance cancer. Both of these studies are disease specific whereas our study covered about EOL care more broadly.

In our qualitative study, participants strongly favoured higher quality supportive care as opposed to prolonging life at all costs, which is consistent with an Australian survey finding that the majority of older adults believe quality of life is 'paramount'.[40](#_ENREF_40) However, participants reported that when making decisions about prolonging life there was inconsistency in the degree to which patient and family had been involved in EOL care contexts. Specifically, participants reported that, health professionals did not always follow patient wishes and advance directives. Factors have been identified before as contributing to this limited involvement of health consumers such as a lack of clear written documentation to facilitate decision-making at the time of admission; [41](#_ENREF_41) clinician-consumer divergent opinion on the prognosis or interpretation of the words ‘terminal’;[42](#_ENREF_42) pressure from relatives;[43](#_ENREF_43) and the relationship between the health professional, patient and caregiver .[44](#_ENREF_44)

The preference to be at home for their EOL care reported in our study is consistent with Foreman and colleagues population survey in Australia over a decade ago that reported 70% of Australians preferred home as a place of death if suffering from a terminal illness. [45](#_ENREF_45) Yet as Pollock[46](#_ENREF_46) (2015) identifies there are difficulties with regard to the management of severe symptoms away from hospitals. Our participants were aware that in many cases home death was not possible due to the challenges of an EOL context, including the increasing care needs as the person deteriorates, the patient-provider relationship, the role and feelings of family or friends who were caregivers, and the availability or feasibility of the health system to provide particular services. Our caregivers also expressed the need for system support to navigate the health care system for loved ones which they often felt unprepared for. Jeff's[47](#_ENREF_47) et al (2017) found similar results in Canadian caregivers of older adults that reported complexity and challenges navigating the health system during interfacility care transitions.

Recent evidence indicates that the use of early community-based palliative care referrals is associated with a reduction in hospital emergency department use in patients with dementia in the last year of life[48](#_ENREF_48) and in reducing cancer patients' transfer to acute hospitals in the last 90 days before death.[49](#_ENREF_49) Consistent with our consumers' preferences, the provision of a palliative care approach in any setting including home-based has shown to enhance satisfaction and increase the likelihood of death at home[50](#_ENREF_50) as well as being more cost-effective .[51](#_ENREF_51) However, existing models of EOL care for frail older adults would require significant changes to be implemented according to patient’s wishes if many prefer to die at home.[52](#_ENREF_52) As is described in the national consensus statement for safe and high-quality EOL care, with an ageing population, a reorganisation of care and the way we manage terminal patients is required.[28](#_ENREF_28)

Despite recommendations on addressing EOL care outside of acute care settings that respect patient preferences to die at home and support informal caregivers,[53](#_ENREF_53) many patients still spend their last days in an acute hospital.[54](#_ENREF_54) Most western health systems do not appear ready for widespread community supported palliative care, as illustrated by previously reported barriers; absence of skilled EOL workforce outside specialist health care facilities; [55](#_ENREF_55) substantial out-of-pocket costs of residential aged care;[56](#_ENREF_56) and the lack of infrastructure to meet demand in countries with universal healthcare has resulted in long waiting lists for eligibility assessment. [57](#_ENREF_57),[58](#_ENREF_58) Failures in organisations to support advanced care planning in partnership with patients, along with ineffective communication will continue to prevent optimal and safe EOL care for the frail older adults.

**Conclusion**

This paper, for the first time, reports on overall EOL care issues and priorities from patients and caregivers in Australian. The study found that patients and caregivers top priorities in EOL management decisions were higher quality supportive care with greater patient and caregiver involvement. This perspective was common across different ethnicities and backgrounds and consistent to those identified in studies conducted overseas and for specific diseases such as cancer and dementia.

**Strengths and Limitations**

This qualitative study involved public consultation and representation of views including those of different ages, ethnicity, and experience of health care. Involving older people as advisors has shown to enhance the relevance of health services research.[33](#_ENREF_33) The information collected in our consultation covered recent experiences in the health system and home settings and is of relevance for clinicians and health service planners. IDI supplemented the FGD findings with extensive details from less physically mobile health service consumers.

A possible limitation of our study is that the majority of participants were females and caregivers. However, as females are often the informal caregivers of chronically ill patients[35](#_ENREF_35) this may in fact be representative of the reality of informal caregivers. The fact that we only conducted three FGD could also be considered as a limitation; however, saturation was rapidly achieved even with three FGD. While our study confirmed that consulting patients and families about this sensitive topic is feasible in Australia, this consultation did not happen at a time of acute medical crisis. It could be argued that our study did not take into account patient and family preferences at those critical times, as studies have shown that preferences can change over time depending on a person's state of health.[59](#_ENREF_59) However, we believe the views our participants are further enriched by the ability for retrospection without the influence of an acute emotion.

**Conclusions**

This paper reiterates the issues and priorities identified by consumers through their experiences of the delivery of EOL care. The themes identified constitute a persistent barrier to the delivery of satisfactory, safe and high quality end-of life-care for consumers. Unfounded perceptions that patients and carers are not open to EOL conversations or shared decisions on goals of care at the EOL including limitation of treatment need to be revisited. With an ageing population, a reorganisation of care and the way we manage terminal patients is required. Failures in organisational support for advance care planning in partnership with patients, inappropriately skilled workforce, unsustainable public demands for aggressive care and ineffective communication will continue to prevent optimal and safe EOL care for the frail older adults.

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**Informed Consent:** Informed consent was obtained from all individual participants included in the study.

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**Figure 1**

**Appendix. Guide for Focus Group Discussion and In-depth Interviews**

*Good afternoon, my name is \_\_\_\_\_\_\_\_ and these are my colleagues….(names)……… Thank you for contributing further to our understanding on aspects that may affect consumers in the delivery of care at the end of life. As you know, this is Round 3 of the consultation and the purpose of this session is to refine our findings based on your views on end-of-life care preferences and what constitutes wellbeing, as derived from the previous two consultations. For the next hour-and-a-half we would like you to exchange experiences, perceptions and learnings about your experiences of participating in decisions for patients/older relatives who are dying or being a caregiver or a healthcare consumer in the context of terminal or chronic advanced illness.*

* *Let me remind you there are no right or wrong answers and the content of all discussions held here will be treated as confidential by everyone.*
* You can choose not to use the real names of people if you use a story to explain your ideas
* Try not to gossip after the group
* Let everyone have a chance to speak and be respectful.
* *Given the sensitive topic area, there is the potential for group members to experience feelings of distress. As you are aware of the purpose of this research and volunteered to openly discuss, we do not anticipate that this will occur too often but should this happen to you, other group members including the investigators can support you on the day, and we have a list of local services where you could find assistance free-of-charge following this meeting.*

*Our reports or manuscripts will summarise comments arising from this discussion but individual participants will not be identified.*

*We have obtained consent from you before this session but remember you don’t have to participate in all questions if you do not feel comfortable or prefer just to talk rather than write, or even if you prefer not to take part.*

Researcher to:

* Ice-breaker/refresher introductions of all participants (as some know each other from previous meetings)
* Check that it is OK with everyone to record the session or part of it
* Go through study information and address questions

*I will introduce each topic area with the opening questions shown and then we will discuss as a group and I will use follow up probes to steer the discussion where necessary. Let’s start with*

**Topic 1: Priorities in EOL care**

* To what extent is end of life care about simply prolonging the length of a person’s survival?
  + How important is their comfort?
  + How important is their quality of life?

**Topic 2: Quality of life factors**

* When you think about quality of life what kinds of things are important to you for a good quality of life?
  + Probes – types of activities that can be done.

**Topic 3: Family impact**

* In what ways does a patient’s health status impact on family life – for example the family day to day routine?
* To what extent is it important that the family agree the appropriate course of care – what kinds of challenges does this raise?

**Topic 4: Healthcare provision**

* What factors are important in the provision of services in end of life care? – provide examples of factors through probes:
  + Probes – honesty, location (home/hospital), cost/affordability, meeting cultural/traditional beliefs.
  + Are there real alternatives to hospital end-of-life care for people living outside large cities? **(This additional question was asked to participant outside large cities in the in-depth interviews**)

*Are there any further recommendations, comments or questions before we close the session?*

**CLOSING**

***Brief oral summary*** *(by facilitator) --Is this an adequate summary? Have we missed anything?*

***Thank you*** *for your time and for sharing your ideas with us today and for being so considerate and respectful of one another.*

***Please remember the ‘no gossip agreement’*** *and that you can talk* *about the Questions and your answers, but not other people or what they say. You can also talk to me or Dr MCM if something said in the group bothers you.*

***So what happens next?***

*After we’ve spoken to all the Advisory Group members, we’ll put everyone’s ideas together as a semi-final draft of the definitions and instruments we are developing. We’ll look at the similar / different ideas and see how today’s comments can enhance what we already know from previous consultations and put these in a report to discuss at the next and final round of consultation. We will be refining some of the patterns in this information and will give you feedback. After this we will test the concepts and instruments in hospital patients as part of another study.*

*I’m sure at the end of the consultation rounds your combined views will be really helpful to other patients, families and healthcare professionals working in this field.*