

# Terminal Care in CKD

KDIGO

Edwina Brown



# A good quality death

- Characteristics of care during the last days of life, which are important from the patient's perspective are:
  - receiving adequate pain and symptom management
  - avoiding inappropriate prolongation of dying
  - achieving a sense of control
  - relieving burden on loved ones
  - strengthening relationships with loved ones

**End of Life Care in Advanced Kidney Disease: A  
Framework for Implementation, Dept of Health, UK 2009**

*Supportive Care Controversies Conference | December 6-8, 2013 | Mexico City, Mexico*



Nephrol Dial Transplant (2012) 27: 1548–1554

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Advance Access publication 6 October 2011

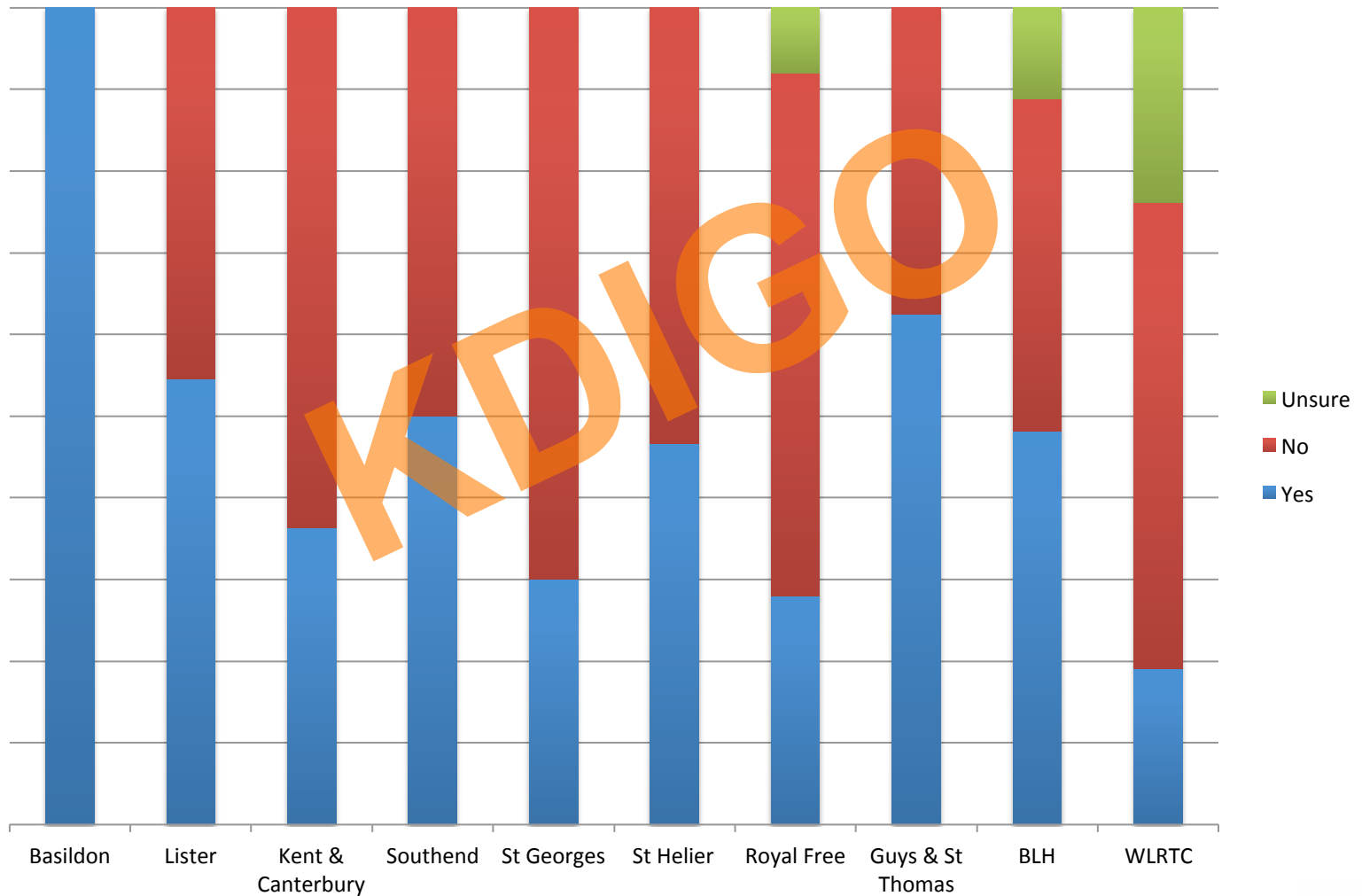
# Measuring the quality of end of life management in patients with advanced kidney disease: results from the pan-Thames renal audit group

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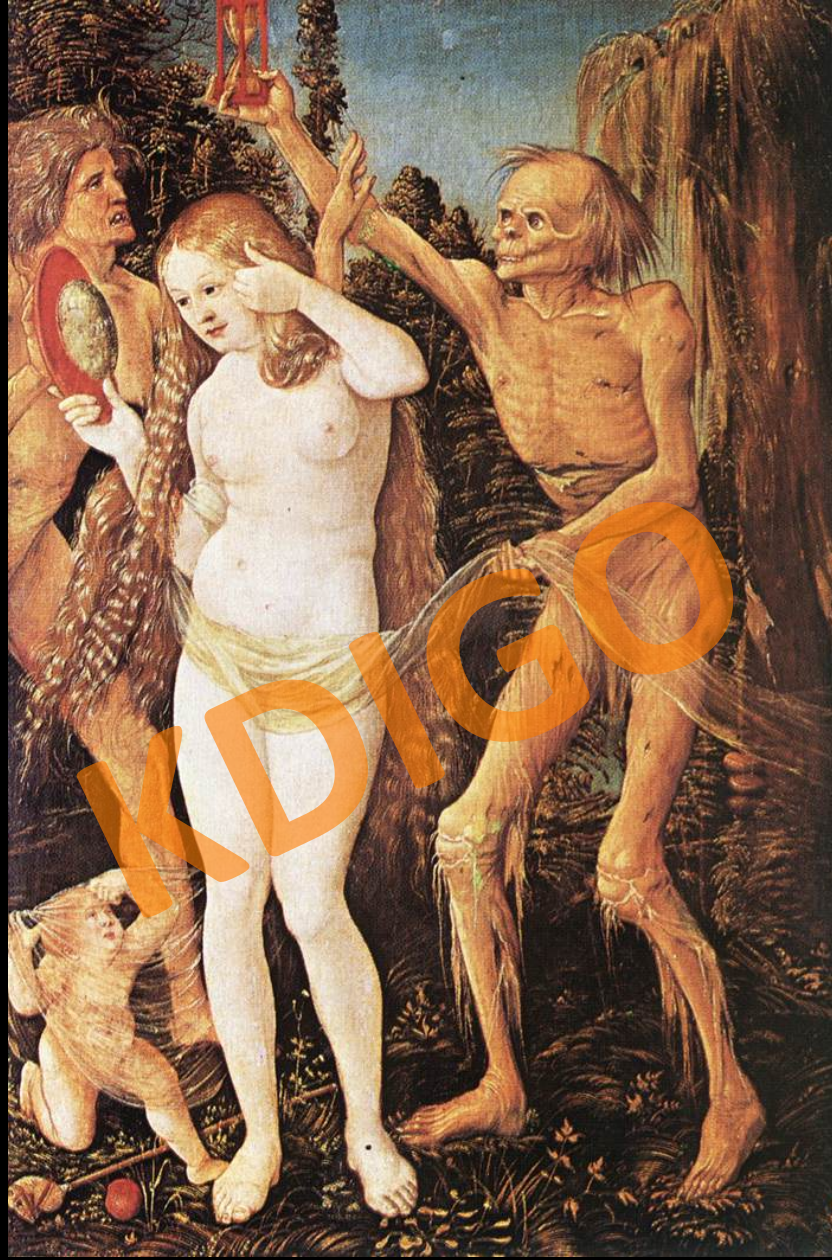


# Palliative Aim by Centre (inpatients)



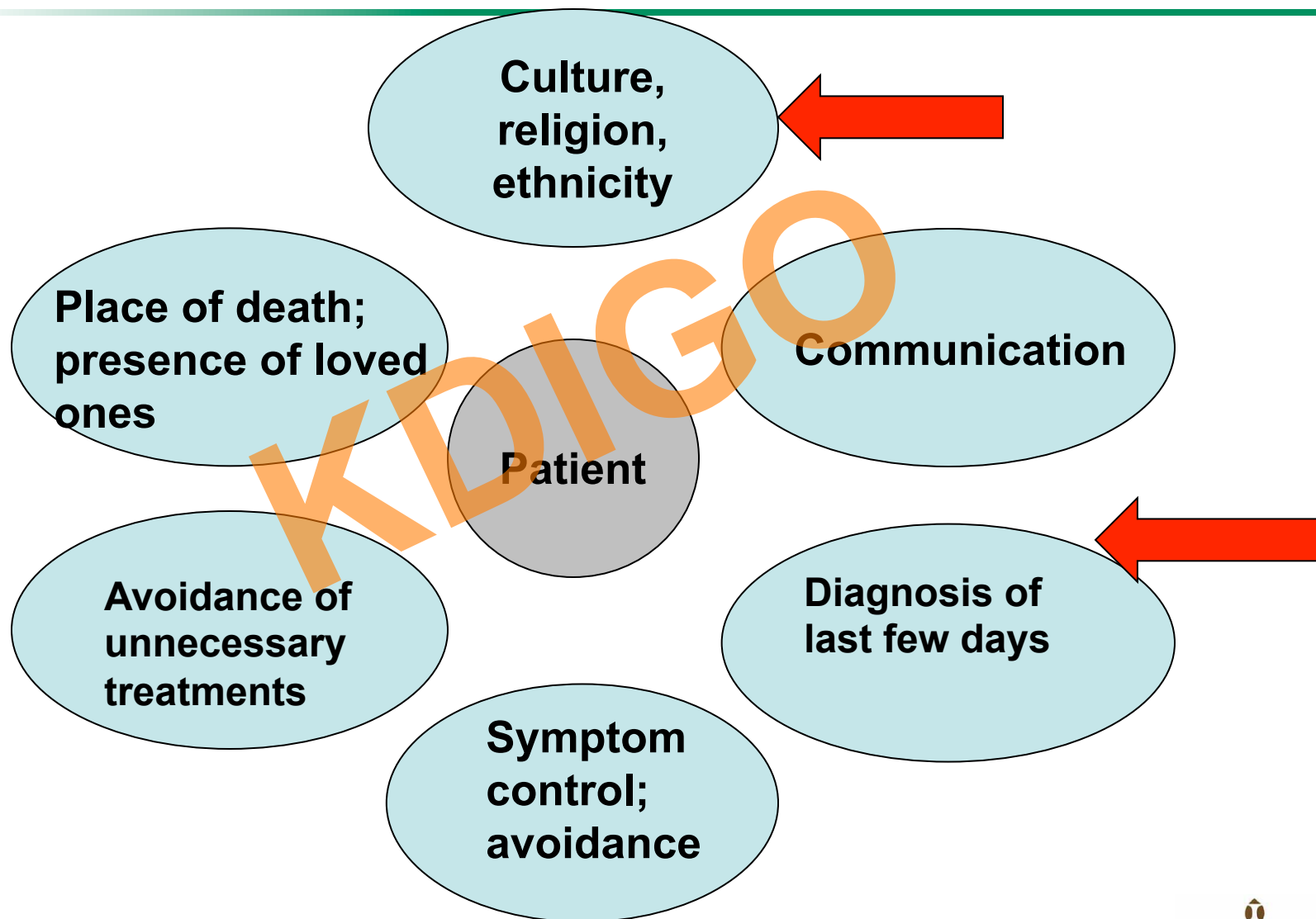
# Unexpected death and quality of dying (inpatients)

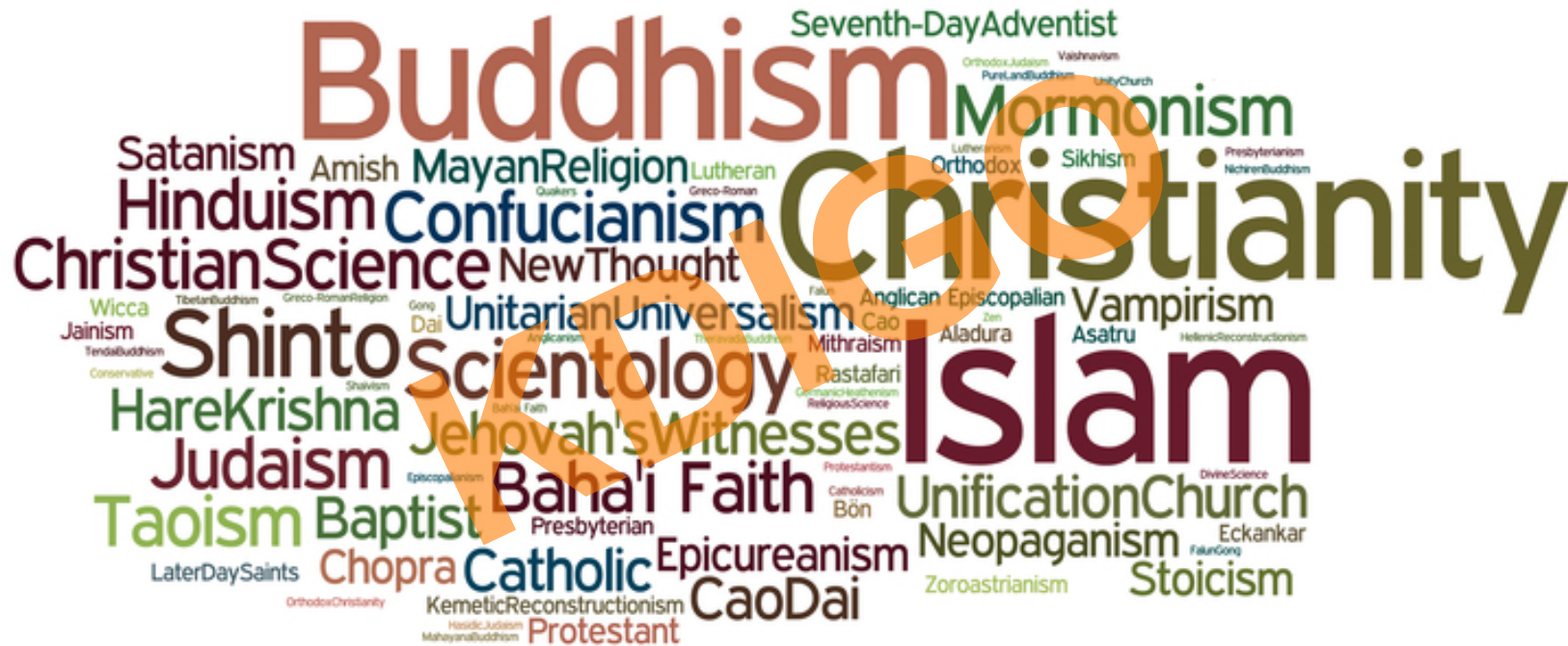
	Unexpected death	Expected death
<b>Number of patients</b>	34 patients	56 patients
<b>Age at death</b>	62 (42-84) years	72 (40-92) years
<b>Length of admission prior to death</b>	13 (0-76) days	23 (0-87) days
<b>“Do not resuscitate” order in place</b>	23%	91%
<b>Dialysis discontinued prior to death</b>	18%	58%
<b>Management changed to palliative care</b>	18%	67%
<b><i>Liverpool Care Pathway</i> used</b>	13%	44%
<b>Patient/Relatives told patient is dying</b>	35%	89%
<b>Good symptom control achieved</b>	47%	58%
<b>Relatives present at death</b>	50%	63%
<b>“Good quality death” as judged by person completing proforma</b>	32%	56%



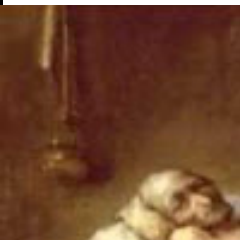
Hans Baldung: "Three Ages of Women and Death" (circa 1484-1545).  
Kunsthistorisches Museum, Vienna

# What affects dying?









# Importance of understanding culture

- Culture is important part of context within which people understand their world and make decisions about how to act
- Failure to take culture seriously may lead to problems such as lack of trust, increased desire for futile aggressive care , unnecessary physical/emotional and spiritual suffering, lack of faith in physician, lack of adherence to treatment regime and dissatisfaction with care

**ANZSN Renal Supportive Care Guidelines 2013.**  
**Nephrology 2013; 18: 401-454**

*Supportive Care Controversies Conference | December 6-8, 2013 | Mexico City, Mexico*



# Cultural competence

- Distrust
- Autonomy
- Decision making and communication
- Truth telling
- Filial responsibility
- Religion/spirituality

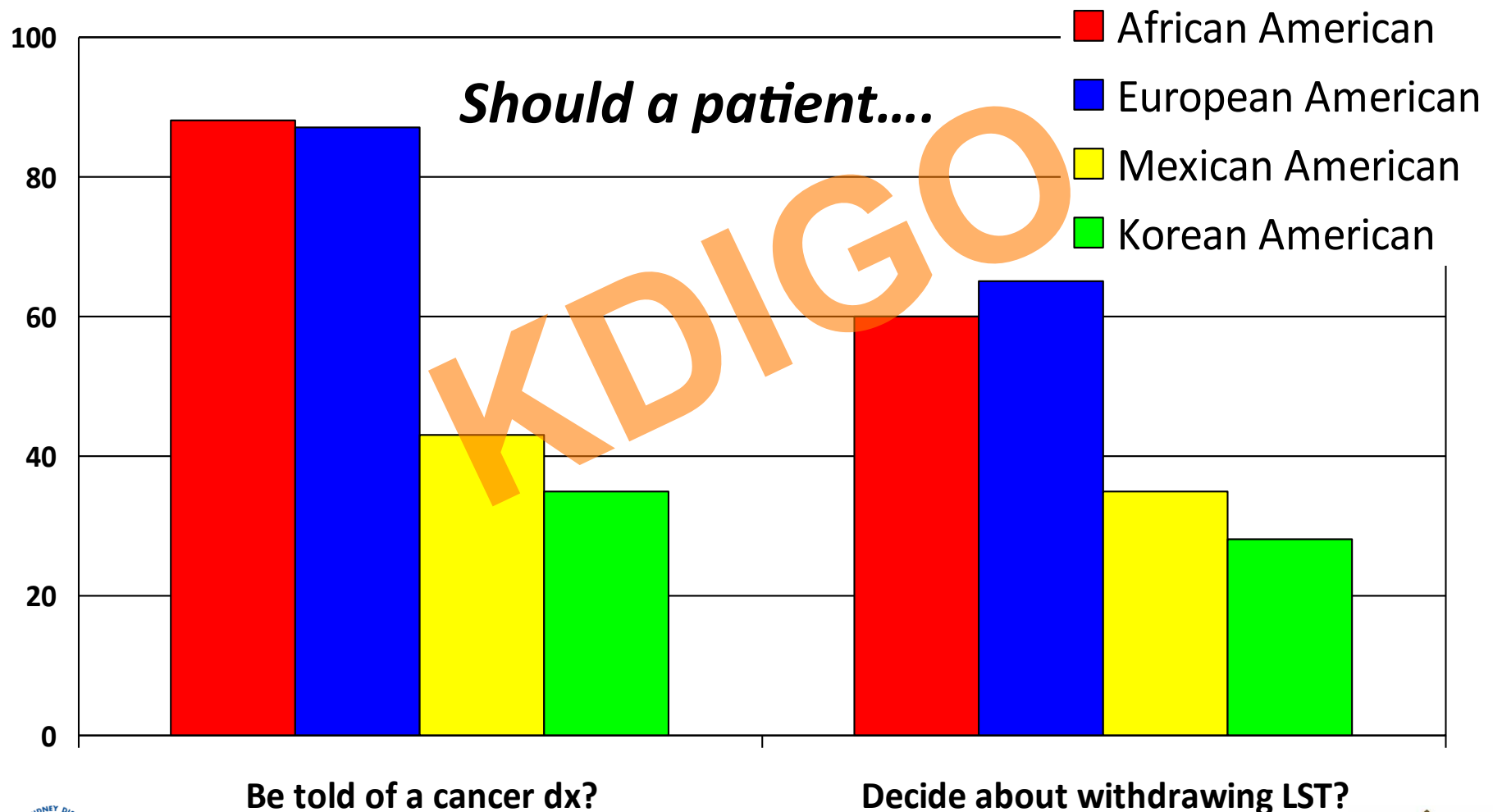
# Decision-making: cultural differences and the medical system

- **Balance of autonomy and beneficence:**
  - UK/USA:
    - emphasis on **AUTONOMY**
  - Europe/Asia:
    - emphasis on **BENEFICENCE**
- **Primary locus of decision-making:**
  - UK/Western Europe/USA:
    - **more often the patient**
  - Asia/Southern Europe and other cultures:
    - **more often the family**

# Truth telling

- Informed consent major tenet in UK/USA health care, but truth telling re diagnosis/prognosis, like cancer, **not norm in some cultures:**
  - Italy, France, Eastern Europe, Asia, Central and South America, and Middle East, HCPs and patients - **withholding medical information more humane**, ethical (Kagawa Singer 2001)
- USA - in the early 1970s, physicians commonly withheld diagnosis of cancer (Oken 1971)

# Cultural differences: survey of 800 patients (Murphy et al 1996)



# Filial responsibility

- Expectation that children will care for parents without question in gratitude for parent's caring and sacrifices
- Hospice may dishonour parents - send message to family as well as to the community that family **unable to provide adequate care**

# Canadian data: HR (95% CI) for race as variable associated with dialysis withdrawal

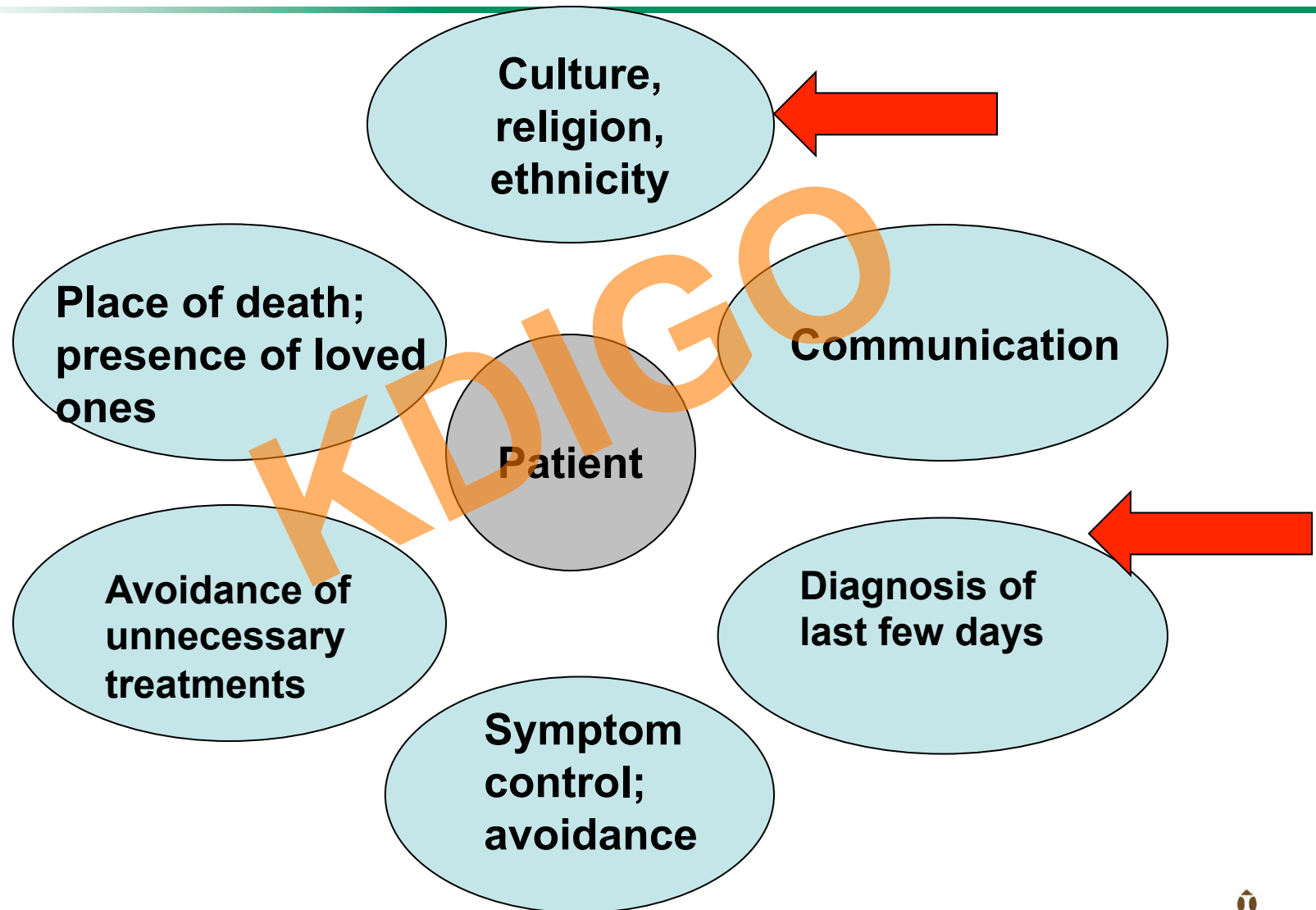
Race	All patients	Age < 75 years	Age ≥ 75 years
White (reference)	1.00	1.00	1.00
Black	0.31 (0.22-0.44)	0.29 (0.19-0.43)	0.37 (0.24-0.56)
Asian	0.38 (0.28-0.51)	0.42 (0.29-0.59)	0.36 (0.25-0.51)
Native Canadian	0.76 (0.59-0.99)	0.87 (0.63-1.20)	0.58 (0.35-0.97)

Ellwood, CJASN 2013





# What affects dying?



# Story of Liverpool Care Pathway

- Attempt in UK to provide “hospice care” for patients dying in hospital
- Paperwork provided pathway to guide inpatient team through communication, symptom control etc of dying process
- Often worked very well and supported by NICE
- BUT not always implemented as planned and became tick box culture

Daily Mail 13<sup>th</sup> Oct 2012

**DID NHS KILL MY MOTHER TO  
FREE BED? THE  
PROFOUNDLY DISTURBING  
STORY BY SON OF PATIENT  
AT CONTROVERSIAL  
TERMINAL CARE HOME**



Daily Mail 14<sup>th</sup> Oct 2012

**CARE? NO THIS IS A  
PATHWAY TO KILLING THAT  
DOCTORS DEEM WORTHLESS**





*Improving Quality*

## Snapshot Review of Complaints in End of Life Care

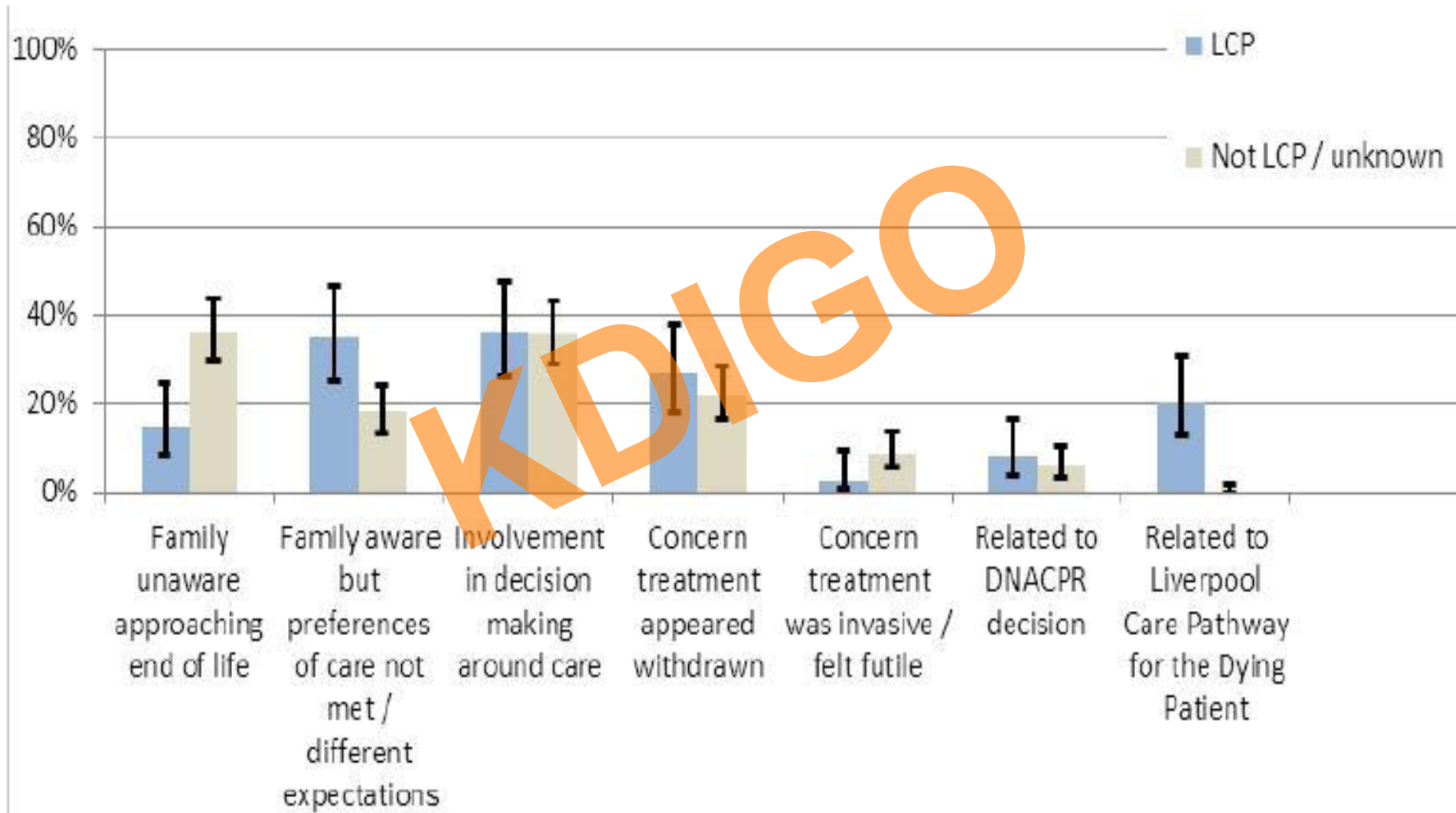
### Key findings

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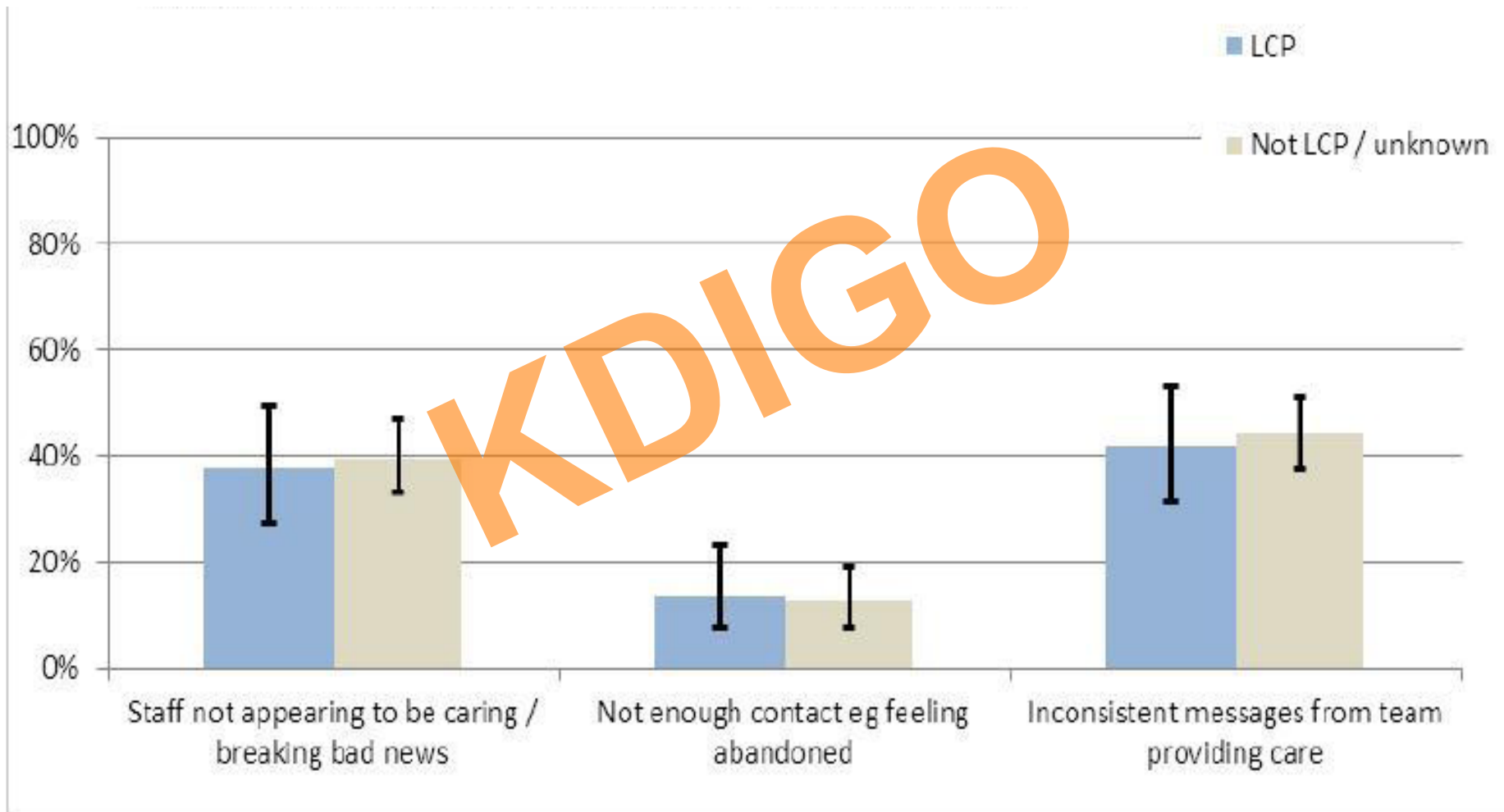
There are few complaints made by bereaved relatives for patients who died in hospital (3 to 7 per cent of all complaints). Even fewer complaints have the Liverpool Care Pathway for the Dying Patient (LCP) as a contributing factor to the complaint.



# Contributing factors to complaints: awareness and involvement



# Contributing factors to complaints



# Sue Ryder Care Centre for the Study of Supportive, Palliative and End of Life Care ... *Understanding and improving palliative and end of life care*



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## RAPID EVIDENCE REVIEW:

## PATHWAYS FOCUSED ON THE DYING PHASE IN END OF LIFE CARE AND THEIR KEY COMPONENTS

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# What is known about predicting death in the next few days or hours?

- Very limited evidence on how to accurately diagnose imminent dying
- Organisational, personal and social factors as well as clinical ones often work against formal diagnosis of imminent dying, particularly in non-cancer patients
- Seems clear that whatever new evidence is produced, there will always be situations where it is not possible to be certain

# What is known about communication in last few days and hours?

- Increasing participation in decision-making increases satisfaction but does not necessarily reduce distress
- Professionals underestimate patients' information needs
- Doctors tend to focus on medical and technological rather than emotional and quality of life
- Style and content affect patients' ability to participate in decision-making
- Good and bad communication experiences have lasting effect on bereaved relatives



# MORE CARE, LESS PATHWAY

## A REVIEW OF THE LIVERPOOL CARE PATHWAY

KDIGO

**July 2013**



*Supportive Care Controversies Conference | December 6-8, 2013 | Mexico City, Mexico*



# Diagnosis of dying

- No precise ways of telling accurately when patient is in last days of life
- Therefore placing patients on LCP can lead to considerable distress in relatives when patient does not die in days or hours
- Doctors and nurses must communicate more honestly about these clinical uncertainties
- More use of, and education and training about evidence-based prognostic are needed
- More research is needed into improving accuracy of these tools

# Decision Making

- Review panel heard many instances of good and bad decision making
- Repeatedly heard stories of relatives or carers visiting a patient, only to discover that there had been dramatic change in treatment
- Unless unavoidable, decision to withdraw or not to start life-prolonging treatment should be taken in cool light of day by senior responsible clinician in consultation with healthcare team – should not be made in middle of night, weekends etc

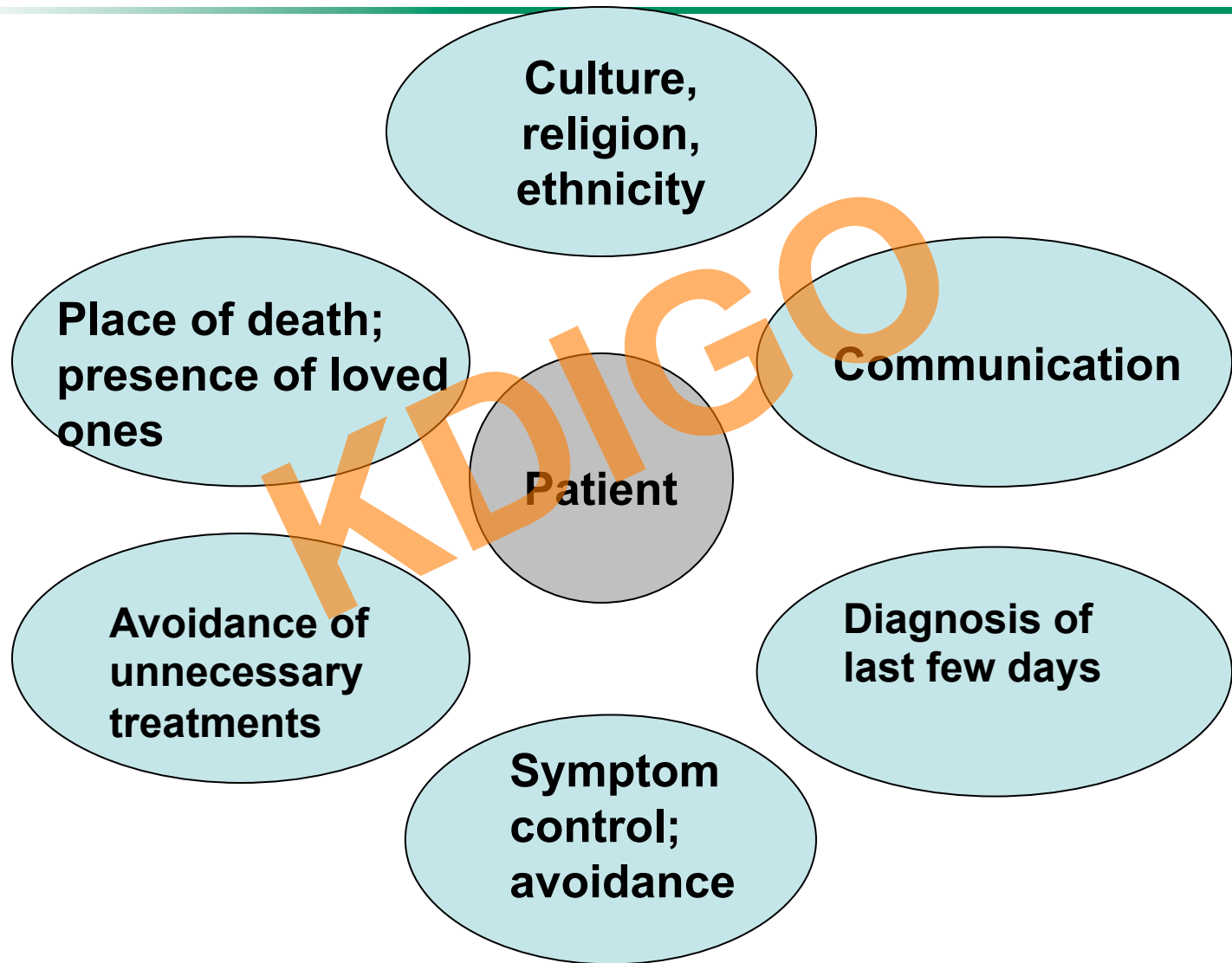
# Sedation and pain management

- Review heard that, if patient became agitated or in greater pain as they died, they often became peaceful because right drugs given at right dose
- Complaints that opiates and tranquilisers being used inappropriately as soon as LCP initiated
- Some of distress experienced could have been mitigated by better communication
- Before syringe driver commenced, this must be discussed as far as possible with patient's relatives or carer and reasoning documented

# Ethical issues

- Some people believe that implementing LCP is way of deliberately hastening death
- LCP entirely reflects ethical principles that should provide basis of good quality care in last days and hours of life
- Any attempt to shorten life is illegal, but no obligation, moral or legal, to preserve life at all costs

# What affects dying?







Edward Munch: Death in the Sickroom, 1893