

EXAMINING THE ROLE OF PATIENT VALUES IN DECISIONS ABOUT LONG-TERM ENTERAL FEEDING: A QUALITATIVE STUDY

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BACKGROUND

Patient experience of living on HEF (Brotherton et al 2006)

Optimal decision making should consider patient values (GMC 2008)


Growing evidence that values clarification aids decision making (fagerlin et al 2013)

Lack of studies focusing on values in HEF decision



AIM

USE THE HINDSIGHT OF PATIENTS LIVING ON HOME
ENTERAL FEEDING TO EXPLORE THE ROLE OF
CONSIDERING PATIENTS VALUES DURING THE DECISION
TO HAVE A GASTROSTOMY PLACED



DEFINITION OF VALUES (STRAUS 2005)

‘THE UNIQUE **PREFERENCES, CONCERNS AND EXPECTATIONS** EACH PATIENT BRINGS TO A CLINICAL ENCOUNTER AND WHICH MUST BE INTEGRATED INTO CLINICAL DECISIONS IF THEY ARE TO SERVE THE PATIENT’

SAMPLE CHARACTERISTICS

Female : Male	4 : 7
Age range (years)	46-80
Time tube in-situ for	1-12 months
ENT Cancer	7
Pancreatitis; Spinal Surgery; Stroke; Dysphagia (no diagnosis)	1 each

Views on decision making

Weighing up the benefits and concerns

Expectations and decision regret

Perceptions of choice

Benefits of
HEF

Concerns of
HEF

Expectations
prior to
gastrostomy
placement

Expectations
of HEF met

Expectations
of HEF not
met

Decision
regret

Felt no
choice given

Felt had a
choice

Felt had no
choice to no
viable
alternative

Concerns

Benefits

Specific

Holistic

Energy

Weight

Survival



BENEFITS

- **PRIMARY HEALTH OUTCOME DRIVERS**

‘COS IT WAS A BIG DECISION FOR ME, BUT WHEN IT COMES TO YOUR LIFE AND LIVING, THERE IS ONLY ONE ANSWER ISN'T THERE. DO WHAT IS BEST FOR ME, AND IF A PEG IS PUT IN THE STOMACH TO FEED. YOU JUST DO IT LIKE.’ (P2)

- **PRAGMATIC DRIVERS**

‘...I JUST THOUGHT I’VE GOTTA HAVE IT IN OR I’M NEVER GOING TO GET HOME FROM HOSPITAL, SO I FELT LIKE A PRISONER.’ (P1)

CONCERNS

‘JUST SOMEONE SITTING DOWN AND EXPLAINING THINGS BETTER TO YOU AND TELLING YOU WHAT COULD HAPPEN AND HOW LONG IT IS GOING TO BE STUCK THERE. NOBODY EVER TOLD ME THAT.’ (P3)

‘SHOULD THEY SAY WELL IT IS GOING TO RESTRICT YOU IN BED AS WELL, IT IS GOING TO RESTRICT THIS, RESTRICT THAT. (...) THEY DON’T GIVE YOU ALL THAT INFORMATION, BECAUSE THEN AT THE END OF THE DAY, YOU WOULD PROBABLY SAY WELL I AM NOT HAVING IT THEN.’ (P2)

EXPECTATIONS

MET

- LESS OF A BURDEN THAN EXPECTED

'I JUST THOUGHT EVERYTHING ABOUT IT WAS GOING TO BE WORSE AND IT IS NOT.'
(P2)

- ABILITY TO ADAPT

'I THINK IF I HADN'T HAD THIS IN, I DON'T THINK I WOULD HAVE BEEN HERE.'
(P10)

NOT MET

- LACK OF POSITIVE OUTCOME

'I JUST THOUGHT IT WERE GOING TO BE RIGHT GOOD. I WOULD PUT WEIGHT ON LIKE THAT, BUT IT'S NOT, IT'S NOT TRUE.'
(P1)

- NOT PREPARED FOR IMPACT OF HEF

'I WASN'T PREPARED FOR THAT AS I WASN'T PREPARED ABOUT WHAT HAVING THE PEG ENTAILED.' (P11)

DECISION REGRET

- MOST DID NOT REGRET HAVING TUBE PLACED

'I COULDN'T HAVE SURVIVED WITHOUT IT. I COULDN'T HAVE SURVIVED WITHOUT THE PEG AND THE FORTISIPS. YOU KNOW, THEY WERE THE ONLY THING THAT WERE KEEPING ME GOING, YOU KNOW.'

(P6)

- TWO REGRETTED TUBE PLACEMENT

'NO I WOULDN'T HAVE HAD IT DONE. I WOULDN'T HAVE HAD IT DONE. I WOULD HAVE STRUGGLED THROUGH SOME WAY OR ANOTHER.' (P3)

CHOICE

- FEW FELT THEY WERE GIVEN A REAL CHOICE
- NO VIABLE ALTERNATIVE


'I READ ALL THE LEAFLETS ON IT AND I THOUGHT MMM, YOU KNOW, WE REALLY NEED TO DO THIS, YOU KNOW. WHERE THE TUMOUR WAS IN THE BACK OF MY TONGUE AS WELL, IT IS ALL WHERE THE SWALLOWING FUNCTION TAKES PLACE ANYWAY SO IT WAS A BIT OF A NO BRAINER FROM THAT SIDE' (P6)

- VARIATION IN VIEWS ON LACK OF CHOICE (PART OF PACKAGE OF TREATMENT)

'WELL NO, THEY DIDN'T DISCUSS IT WITH ME, THEY JUST SAID THAT SOME PATIENTS HAVE PROBLEMS SO I WAS HAVING A PEG FITTED. THAT WERE IT. IT WEREN'T DISCUSSED. IT WEREN'T EXPLAINED. NOTHING. IT WERE JUST I AM HAVING A PEG FITTED.' (P3)



IMPLICATIONS FOR PRACTICE

- RECOGNISE COMPLEX NATURE OF DECISION MAKING – NOT ONE SIZE FITS ALL
 - DECISION MAKING APPROACH MAY NEED TO BE PATIENT OR CONDITION SPECIFIC AND REQUIRES KNOWLEDGE OF HEF IMPACT
 - SHOULD WEIGH UP RISK OF ANXIETY WITH NEED FOR INFORMED CONSENT
 - CHALLENGE TO GIVE BALANCED VIEW TO PREPARE FOR LIFE ON HEF
 - FURTHER RESEARCH NEEDED
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DECISION QUALITY OUTCOMES

- IS THERE A NEED TO MEASURE DECISION QUALITY E.G. DECISION REGRET; DECISION SATISFACTION; DECISIONAL CONFLICT?
- ROLE FOR A DECISION MAKING PREM?
- DECISION SUPPORT OUTCOMES COULD SUPPORT MORE PROMINENT ROLE FOR THE HEF DIETITIAN DURING DECISION MAKING?