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Young adults' experiences of dialysis and kidney transplant decision-making

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Overview

- Background to the study
- Research Question and Aims
- Methods
- Findings
- Conclusion

Background

Young adults experience

- Poor outcomes and increase risk compared to healthy age-related peers, children and older adults (Park et al. 2014; Ferris et al. 2016)

- Face complex decision-making including dialysis and kidney transplant decisions (Ferris et al. 2016)

- Evidence suggest that over 50% of young adults started haemodialysis as their first kidney failure treatment and less had pre-emptive kidney transplantation (Hamilton et al. 2018), but this pattern is less understood

- Less literature with specific focus on young adults experiences of the decision-making process and its effect from their perspective (Ofori-Ansah et al. 2021)

Research question and aims

- Formed steering group (6 people) to shape the research idea.

- **Research question**
- **How do young adults with end-stage kidney disease experience dialysis and/or kidney transplant decision-making?**

- **Aims**
- Explore young adults lived experiences of making dialysis and kidney transplant decision to understand the meaning of their experiences.
- Investigate the effect of decision-making and choice on young adults' well-being.

Methods

- **Qualitative Study**
  - Interpretive Phenomenological Approach
- **Inclusion criteria**
  - Young adults aged 18 to 30 years with kidney failure diagnosis greater than 3 months
  - Made decisions about replacement therapy treatment options
  - Has capacity to give consent
- **Exclusion**
  - No capacity, diagnosed less than 3months
  - Non English speaking

Data collection

- Semi structured interviews was conducted
- Recorded electronically and transcribed verbatim
- Thematic analysis conducted

Sample size

20 participants with end–stage kidney disease

Purposeful sampling

- Involved gate keepers, kidney patients charity groups.
- Developed short video to promote awareness of the study
- Social media network (Facebook, Twitter, internet & email)

Findings

- **Involvement in decision-making made young adults world turn-upside down**
  - Experienced a change in their self-identity
  - Experienced Life thrown off track

- **Young adults experienced varied communication about options**
  - Suboptimal information delivery
  - Inadequate health literacy due to lack of information, knowledge and understanding of CKD and treatment options
  - Lacked access to peers with experiential knowledge
  - Benefits/positive-led information delivery with lack of/minimal information on risks

Findings

- **Young adults experience inequalities during engagement in decision-making**
  - Not invited to decision-making an equal and lacked choice
  - Decision preference and roles not always elicited
  - Have preference for autonomous and shared decisional roles
  - Voice not always heard, believed or listened to

- **Experience of the new normal**
  - Lack of prepare for choice
  - Experience of choice different from what was promised/believe to happen
  - Feeling abandoned (those who transitioned to adult kidney centre)
  - Felt different – not normal, low self-esteem, low self-confidence
  - Struggled to perform therapy
  - Decisional regrets (anger, guilt, self-blame)

Impact of decision-making and choice

- **Psychological impact**
- Emotional and psychological burden (fear, anxiety and depression)
- Under estimation of psychological burden by clinicians

- **Physical impact**
  - Lack of energy, constant fatigue and body image issues

- **Social impact**
  - Feeling trapped in the circle of treatment performance Became socially isolated

- **Educational impact**
- Disruptions to academic life, attendance, school work load and playing catch ups
- Underachievement in education, employment and family life compared to aged-related peers
- Struggled to cope and lacked psychosocial support

Implications for practice

- Young adults need to be invited into the decision-making context and treated as equals
- Young adults must be made aware that choice exists
- Offer choice instead of suggesting choice or making decisions for them or using indirect coercion
- Work with young adults to find their informational needs
- Provide individualised balanced and quality information on disease and options
- Education on disease and options should start early and built on gradually
- Incorporate assessment of young adults' knowledge and understanding of options during education

Implications for practice

- Engage in collaborative discussions in a non threatening way
- Clarification of young adults’ role in the decision-making context
- Young adults have preferred roles which evolves over time based on knowledge and understanding
- Young adults prefer autonomous and shared decision roles
- Offer peer support to provide experiential knowledge
- Young adults need to be prepared for decision-making and choice
- Psychosocial support must be form part of the decision-making process and not as a separate thing

Conclusion

- Young adults have unmet decisional needs
- Decision-making makes young adults world turn-upside down
- Experience change in their self-identity and throw their life off track
- Young adults experience low health literacy of disease and treatment options due suboptimal and lack of information
- Young adults’ experience inequalities in decision-making and unable to engage as an equal
- Decision-making and experience of choice impacts on the physical, psychosocial and mental well-being of young adults
- Struggle to cope
- Lack psychosocial support

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