Service Related Project Presentation

Exploring the psychological needs of patients receiving a transplant in a National Health Service Transplant unit

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2014 COHORT
Aims of this presentation

- Introducing topic and rationale
  - Why is the current research important?

- Outline aims of the research, methods and analysis

- Discuss themes generated from research data

- Consider service implications/future research

- Conclusions
Organ transplantation is the process of transferring cells, tissues or organ from a donor to a recipient, to restore bodily function (WHO, 2015).

Development of improved immunosuppression in 1980’s (Starzl et al., 1985) led to fewer rejections and better patient outcomes.

NHSBT (2015) documented transplant activity 2014 – 2015:
- Over **7000** individuals awaiting transplant across UK
- High numbers of patients on waiting lists for long periods – impact’s psychological health
- Mauthner et al. (2013) – Patients in pre-transplant stage experience feelings of fear, anxiety and predominately **Loss**
- Need useful information and consistent support
Psychological health of transplant patients:

- Depression can affect up to 60% of transplant patients at some stage (Corbett et al., 2013)
- Lung transplant recipients have particularly low quality of life pre-transplant (Ortega et al., 2009)
- The psychological health of patients should be a main focus throughout process; individuals should be supported to deal with the changing needs and challenges that arise as they move from pre to post transplant

- Literature identified links between psychological health and long term survival in this demographic (Rosenberger et al., 2016; Smith et al., 2015)
  - Importance of individuals being encouraged and supported to be psychologically healthy

- What are the needs of patients, in order to support their recovery and wellbeing?
Research was conducted within an **NHS cardiothoracic (Heart and lung) transplant unit** in England

- Research question and aims considered in collaboration with psychologists working in the service
- Focus on patient perspective to improve understanding

**Research question**: Explore the experiences of individuals who have undergone transplant within an NHS transplant unit

**Aim**: To increase understanding of what patients informational and support needs are, and how these change through their experience from pre to post-transplant. Findings would have important implications for how the service develops future informational resources and organises support opportunities for both patients and their loved ones.
Methods

- **Design**
  - Qualitative research
  - Ethic approval sought through NHS and local R&D

- **Participants**
  - 7 men
  - Age range: 40s - 65
  - All recipients of a lung transplant

<table>
<thead>
<tr>
<th></th>
<th>Diagnosis</th>
<th>Time on waiting list</th>
<th>Time since transplant</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albert</td>
<td>Emphysema</td>
<td>12 + months</td>
<td>3 years</td>
<td>63</td>
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<tr>
<td>Daniel</td>
<td>Pulmonary Fibrosis</td>
<td>6 months</td>
<td>1 Year</td>
<td>50s</td>
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<tr>
<td>Herbert</td>
<td>Sarcoidosis</td>
<td>16 months</td>
<td>6 months</td>
<td>40s</td>
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<tr>
<td>Malcolm</td>
<td>COPD</td>
<td>5 months</td>
<td>3 years</td>
<td>65</td>
</tr>
<tr>
<td>Sidney</td>
<td>Emphysema and COPD</td>
<td>1 week</td>
<td>4 years</td>
<td>64</td>
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<tr>
<td>Joe</td>
<td>Primary pulmonary hypertension</td>
<td>3+ years</td>
<td>5 years</td>
<td>40s</td>
</tr>
<tr>
<td>Tom</td>
<td>Emphysema</td>
<td>3 weeks</td>
<td>5 years</td>
<td>59</td>
</tr>
</tbody>
</table>
Data collection and Analysis

- Semi-structured interviews conducted; 6 within the transplant unit and 1 in a participant’s home. Each interview lasted approximately 1 hour

- Interview schedule facilitated flexible discussion. Questions developed to make participants reflect on their experience:
  - How did your support needs change throughout the process? What information was most beneficial to you? Did certain information become more important at different stages in the process?

- Analysis conducted using **Interpretative Phenomenological Analysis**
  - “Examining how individuals make meaning of life experiences” (Pietkiewicz & Smith, 2014, p.14)

- Transcripts analysed individually; codes generated from transcripts were iteratively grouped and reviewed to identify final themes
Results

- 4 final themes generated from the data:
  - **Theme 1**: Emotional impact of the pre-transplant process
  - **Theme 2**: Gaining information and developing expectations
  - **Theme 3**: Identifying and satisfying support needs
  - **Theme 4**: Adapting to post-transplant life
Emotional Impact of the pre-transplant process

- Participants discussed experiencing **fear and anxiety**, which had an impact on their ability to remain positive and led to considerable thoughts around mortality.

- Experience was described as extremely **isolating** for individuals; they pushed people away or felt unable to connect with others. Each man discussed their varied ability to and techniques for seeking comfort and support, to come to term with their situation.

- **Loss** pervaded all participant accounts; loss of role, autonomy, control and independence. This continued post-transplant, with the men limited by the need to adhere to rules to maintain health.

- Each participant emphasised pre-transplant as a stage of particular vulnerability, where needing help is necessary, but accepting it is hard.
Gaining information and developing expectations

- **Good connections forged with professionals** important for developing realistic expectations

- Participants felt it was easier to gain information relating to pre-transplant/surgery stage than information about post-transplant/recovery stage

- Professionals must be aware of patient anxiety and level of knowledge – “You find that doctors know something and they think you know as well...Like I hate people using abbreviations. What the hell does that mean?” (Malcolm)

- Important for patients to feel prepared for recovery stage – Hallucinations, psychological, social and physical side effects
  - Current information resources do not adequately prepare individuals

- Being informed increased individuals feeling of preparedness and control – Lack of information led to greater anxiety and difficulties coping post-transplant
Identifying and satisfying support needs

- Psychology input/role highlighted by participants as **useful and important** resource
  - Saw psychology as an ‘ally’ (Tom) and more approachable than doctors

- Several men didn’t meet with psychology until in the **post-transplant stage** – would have found earlier input beneficial. Feel that psychology should have a larger role in their care and be more present throughout the experience.

- Benefit of **flexible and individualised** support
  - Some couldn’t attend organised support groups – felt they missed out on useful support

- Usefulness of peer support – sense of camaraderie
  - Benefit of opportunities to meet together and discuss experience – things doctors don’t explain
Adapting to post-transplant life

- Each individual went through a period of adjusting to ‘new life’ – mourning what they had lost, while coming to terms with improved health and the challenges that come with new organ
  - Life gaining new perspective

- Sense of fragility in men’s accounts – Identified psychological aspects of recovery, which men need continued support with

- Side effects were a prominent part of patient experience; individuals reported feeling that more detailed and balanced information would be useful, as would support coming to terms with side effects, some of which are life long

- Each man discussed ‘personal responsibility’ and giving back as part of their role in recovery
  - Following rules/looking after themselves and assisting future patients was of particular importance
Discussion and service Implications

Results illustrated how challenging the transplant experience is and also the influence which good information/support can have on the development of realistic expectations, coping and recovery.

Participants identified:
- The importance of comprehensive information for patients and loved ones, suitably communicated
- The need for psychological input and monitoring, to ensure patients are being adequately supported. Re-evaluation of how psychology assesses, monitor and support patients
- The benefit of peer support and patients being aware of what support resources are available to them

Supports previous research:
- Having appropriate preparatory information early in the process influences post-surgical psychological and physical outcomes (Auer et al., 2015)
- Peer support provided access to practical information, positive coping models and empowered individuals (Hughes, Wood & Smith, 2009)
Conclusions

Service implications:
- Promoting a consistent environment and staff team that empowers patients, makes them feel involved in their care and able to seek information
- Consideration of opportunities for patients and their loved ones to seek information out with arranged appointments; E.g. drop in sessions, online or telephone consultations
- Patient input in the development of future information resources
- Revised methods of how psychologists assess and monitor patient support needs
- Development of future support group opportunities

Future Research
- Research around which methods of communication are preferred by patients/loved ones could assist with the future development of information/support resources
- A more novel research area could be around patient experience of post-surgery hallucinations, and how they can best be informed/supported in dealing with this experience
Reflections

- A challenging, but positive learning experience
- Gained experience of applying for NHS and local R&D ethics – good practice for thesis
- Useful experience with regards to learning to analyse, code and transcribe qualitative data
- Encountered difficulties recruiting heart transplant recipients due to my availability at outpatient clinics and the expertise of clinicians who agreed to assist with recruitment
  - Would be interesting to see if another study looking at heart patients found similar or different themes
References

- NHSBT. (2015)
- Smith (2015).
- Auer et al 2015
Thank you for listening!

ANY QUESTIONS?