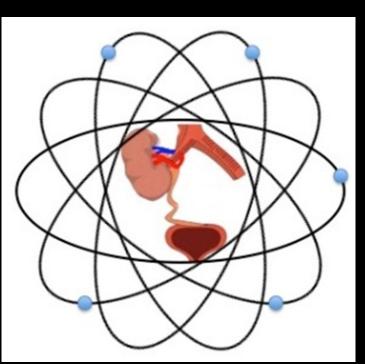
# Comparing quality of life following simultaneous pancreas and kidney transplantation and kidney only transplantation: A qualitative interview sub-study of the ATTOM programme

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#### Introduction

Simultaneous pancreas and kidney (SPK) transplantation is increasingly used as a treatment for chronic kidney disease (CKD) in people with Type 1 diabetes. Prior studies have focused on the impact of SPK on health status rather than on quality of life [1-3]. As part of the NIHR-funded Access to Transplantation and Transplant Outcome Measures (ATTOM) programme patients with CKD including SPK recipients with diabetes or deceased-donor Kidney Alone (KA) recipients with or without diabetes were interviewed to investigate and compare the impact of their treatment on their quality of life (QoL).

#### Methods

Semi-structured in-depth telephone interviews:

♦ examined the impact of diabetes and the renal condition on QoL.

Patients selected based on their:

- ◆ average weighted impact (AWI) scores on the Renal Dependent Quality of Life (RDQoL) questionnaire [4]
- ◆ AWI scores above or below one standard deviation of the mean for each group.

Patients included:

- ◆ 10 KA transplant recipients (5 women, 3 pre-emptive)
- ♦ 10 SPK transplant recipients (4 women, 4 pre-emptive).

Analysis:

♦ thematic and interpretative phenomenological analyses.

# Results

# Theme 1: The need to hold realistic expectations of transplantation

- being advised of potential risks and problems was advantageous
- overly optimistic patient expectations related to poorer QoL post-transplant.

# Theme 2: Anxieties re: transplant failure

- ♦ all SPK patients vs. only 2 KA patients with history of previous transplant aware of possible transplant failure
- ♦ two thirds of SPK recipients check their blood glucose levels regularly or avoid sugar intake.

# Theme 1 Example Quotes

Some people would welcome a (poorly functioning) kidney like mine, the treatment I have had and the result I've got because it's much better than being on dialysis. But that's not what I wanted. I wanted an improvement for my life not the other way around.

Woman, pre-emptive KA transplant, waitlisted 1.5yrs, low QoL

It did shock me because I didn't think (the SPK scar) would be from, like from breast bone down to the groin... I never thought it would be that big.

Woman, SPK transplant, continuous ambulatory peritoneal dialysis (CAPD) 7m, low QoL

(the professor) who's the main transplant man, he said ... once you've had (the SPK transplant) done, you'll feel so appalling, you'll think why on earth have I done that? So they are, actually they're brutally honest and actually I think they prepare you extremely well.

Man, pre-emptive SPK transplant, waitlisted 16m, low QoL

I became suddenly very ill and I had developed renal artery stenosis, which is a very rare and very serious complication Woman, KA transplant, haemodialysis (HD) 13m, high QoL

# Theme 2 Example Quotes

I test my blood once... once a week now just every now and again.

That's for my own benefit rather than anything else.

Man, SPK transplant, on HD previously for 6m, high QoL

I monitor myself every few days whereas before it was every day, 8 to 10 times a day. I do it every two days and I do it twice every two days.

Man, pre-emptive SPK transplant, waitlisted 4yrs, low QoL

(At first) I kind of couldn't bring myself to eat anything (with sugar in it) after so long (restricting my sugar intake).

Woman, pre-emptive SPK transplant, high QoL

## **Implications**

Appropriate information needs to be provided to manage expectations of transplant for all patients, particularly in relation to possible complications that may occur with transplantation. SPK patients have more adjustment challenges following transplant and some seek a more active role in their care. Discussion with patients is needed about how their newly transplanted pancreas and QoL can best be protected.

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