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WHY TAKE THE CHANCE: A QUALITATIVE GROUNDED THEORY STUDY OF NOCTURNAL HEMODIALYSIS RECIPIENTS WHO DECLINE KIDNEY TRANSPLANTATION

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5 1 WHY TAKE THE CHANCE: A QUALITATIVE GROUNDED THEORY STUDY OF
6 2 NOCTURNAL HEMODIALYSIS RECIPIENTS WHO DECLINE KIDNEY
7 3 TRANSPLANTATION
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29 24 **KEY WORDS:** Decision making, grounded theory, nocturnal hemodialysis, transplantation
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5 27 **ABSTRACT:**
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9 28 **Objective:** The objective of this study was to examine the factors that influence decision-making
10 29 to forgo transplantation in favor of remaining on nocturnal hemodialysis (NHD).
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15 32 **Design:** A grounded theory approach using in-depth telephone interviewing was used.
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19 35 **Setting:** Participants were identified from two tertiary care renal programs in Canada.
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23 38 **Participants:** The study participants were otherwise eligible end stage renal disease (ESRD)
24 39 patients who have opted to remain off of the transplant list. A total of seven eligible participants
25 40 were interviewed. Five were male. The mean age was 46 years.
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27 42

28 43 **Analysis:** A constant comparative method of analysis was used to identify a core category and
29 44 factors influencing the decision-making process.
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32 47 **Results:** In this grounded theory study of people receiving NHD who refused kidney
33 48 transplantation, the core category of “why take a chance when things are going well?” was
34 49 identified, along with four factors that influenced the decision including “negative past
35 50 experience”, “feeling well on NHD”, “gaining autonomy”, and “responsibility”.
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5 48 **Conclusions:** This study provides insight into patients' thought processes surrounding an
6
7 49 important treatment decision. Such insights might help the renal team to better understand, and
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9
10 50 thereby respect, patient choice in a patient-centered care paradigm. Findings may also be useful
11
12 51 in the development of education programs addressing the specific concerns of this population of
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14 52 patients.
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19 54 **STRENGTHS AND LIMITATIONS OF THIS STUDY:**

- 20
21 55 • The use of grounded theory allowed for the development of a testable theory for
22
23 56 understanding patient decision-making.
24
25 57 • Interviews enable an in-depth and detailed examination of patients' experience.
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27 58 • The rarity of this phenomenon made obtaining a large sample difficult.
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29 59 • All participants undertook traditional dialysis modalities prior to starting NHD; therefore
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31 60 their experiences may not be representative of patients who have only even done NHD.
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63 INTRODUCTION:

64 The emergence of nocturnal home hemodialysis (NHD) in the mid 1990s was seen as a
65 welcome addition to ESRD treatment options.[1] NHD is typically self-administered 4-6 nights
66 per week, while the patient sleeps, with each treatment lasting 7-9 hours.[2] By increasing the
67 frequency and duration of dialysis, this treatment improves markers of mineral metabolism,
68 reduces dependence on antihypertensive medications, liberalizes dietary restrictions, and results
69 in better health-related quality of life when compared to conventional hemodialysis.[3] Evidence
70 suggests that this intensive dialysis provides superior patient survival compared to conventional
71 hemodialysis, perhaps similar to deceased donor transplantation.[2, 4, 5, 6] Notwithstanding
72 these observations, clinicians appropriately continue to advocate for transplantation for all
73 suitable candidates,[7] since kidney transplantation is generally regarded as the gold standard
74 treatment for those with end-stage renal disease (ESRD).[8-11]

75 An environmental scan of two large well-established home hemodialysis programs in
76 Canada reveals that approximately 15% of transplantable patients on NHD choose to forgo the
77 gold standard treatment, despite being otherwise medically eligible. This is often against the
78 advice of their care team. It is not currently known why patients choose to remain on NHD when
79 a presumably better treatment is available. Hence, the objective of this study was to examine the
80 factors that influence decision-making to forgo transplantation in favor of remaining on NHD.

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82 SUBJECTS and METHODS:

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84 Design:

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5 85 A qualitative study design, applying grounded theory, was selected to enable the description and
6
7 86 exploration of the basic social process leading to the decision to decline transplantation.[12]
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10 87 Grounded theory supports theory development through the identification of core categories.[13]
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15 89 **Sample and sampling:**

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18 90 We selected a purposive sample of NHD recipients who declined transplantation. Patients were
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20 91 recruited from two home hemodialysis programs: the Northern Alberta Renal Program (NARP)
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22 92 and the Toronto General Hospital – University Health Network. Patients were eligible if they
23
24 93 were over 18 years of age, English-speaking, had received NHD for at least 3 months, and
25
26 94 declined wait listing for kidney transplantation. Patients were excluded if they were not eligible
27
28 95 to be transplanted for any reason (e.g., prohibitive comorbid conditions). All participants
29
30 96 provided written informed consent to a third party not otherwise involved with this study, or
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32 97 patient care. Ethics approval was obtained from the Health Research Ethics Boards at the
33
34 98 University of Alberta and the University of Toronto. The research activities being reported are
35
36 99 consistent with the Principles of the Declaration of Istanbul.
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41 101 **Data collection:**

42
43 102 Semi-structured telephone interviews were conducted with each participant because of the wide
44
45 103 geographic distribution of the participants. Telephone interviewing has been validated in
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47 104 qualitative research to obtain rich descriptions about sensitive topics.[14] All interviews were
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49 105 conducted by MR, who was trained and experienced in conducting such interviews, and who had
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5 106 no prior relationship with study participants. Interviews started with open-ended questions
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7 107 regarding participants' experiences with NHD, and perceptions of transplantation, followed by
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10 108 more detailed and probing questions depending on responses. Interviews lasted 20 minutes to 2.5
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12 109 hours (median time of 30 minutes). All interviews were audio-recorded and transcribed verbatim.
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14 110 Field notes were recorded for each interview.
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17 111 Baseline clinical information was collected by chart review. This included demographic
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19 112 data, comorbidities, dialysis prescription, and measures of routine laboratory variables. These
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21 113 data were used to verify participants' eligibility for kidney transplantation by two independent
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23 114 transplant nephrologists (SC and JK).
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31 **Analysis:**

32 117 A constant comparative approach, wherein every piece of data was compared to other pieces of
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34 118 data was used to identify common themes and a core category.[15] Research team members MR,
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36 119 AM, and RP, independently examined and coded the interview transcripts, and met on three
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38 120 separate occasions, two of which were during the active data collection phase, to discuss
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40 121 interview findings (MR is qualitative methods expert, AM is an experienced qualitative
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42 122 nephrology researcher, and RP is a clinician nephrologist/epidemiologist). This approach
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44 123 resulted in refinement of future interview questions to probe participants about subjects raised by
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46 124 previous participants and added depth to the interviews. Data collection continued until no new
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48 125 findings or themes emerged (i.e., saturation).
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127 **RESULTS:**

128 A total of seven participants were interviewed; five were male. The mean age was 46 years

129 (range 39-55). Six of the participants were employed; the seventh was a full-time student. Each

130 had been on NHD for at least one year, with some using this therapy for more than 10 years.

131 More detailed participant characteristics are summarized in Table 1.

132

133 Table 1 – Participant characteristics¹

	Participants						
	1	2	3	4	5	6	7
Years with ESRD	23	14	5	14	12	11	12
Nights per week of NHD	4	5	3	5	6	4	5
Hours per night of NHD	8	7.5	9	8	7.5	8	8
History of cancer	No	Yes ²	No	Yes ²	No	No	Yes ²
History of ischemic heart disease	No	No	No	No	No	No	No
BMI (kg/m ²)	26.2	31.5	29.7	28	26.2	24.4	20.1
Albumin (g/dL)	44	36	43	40	33	38	38
Calcium (mg/dL)	2.66	2.28	2.71	2.62	2.31	2.25	2.55
Phosphate (mg.dL)	2.06	1.10	1.57	2.49	1.36	1.51	0.93
Hemoglobin (g/dL)	103	98	133	121	119	138	108
Antihypertensive drug use	No	No	No	Yes	No	Yes	No

134 ¹ Respondent characteristics including age, gender, race, underlying disease, previous transplant history, and current
 135 employment status have not been included in this table to comply with norms in the publication of qualitative
 136 research designed to maintain confidentiality.[19]

137 ² Respondent was cancer free at the time of decision re: transplant

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5 139 The following sections outline the interview findings beginning with an overview of the
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7 140 core category, “why take a chance when things are going well?”, and a description of the
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10 141 medical, psychological, and social factors contributing to this category.
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12 142

14 143 **Why Take a Chance when Things are Going Well?**

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17 144 This category reflected participants’ active assessment and weighing of the medical and social
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19 145 risks/benefits of the therapy in question prior to making a decision. Overall, participants reported
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1 146 general satisfaction with their current health and circumstances. Each participant discussed being
2
3 147 able to pursue activities important to her or him, including having children and traveling, and did
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5 148 not feel limited by their health condition.

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8 149 While at the time of the interviews, none of the participants was actively pursuing
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0 150 transplantation; it was also evident that this decision may change if circumstances changed. For
1
2 151 example, Participant 7 mused about having a transplant in the future and stated, “if it
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4 152 [transplantation] gives me 10, 15 years without the machine, I’ll be 55-ish...’cause even though
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6 153 having it [dialysis] at home is great, but it’s still a machine, you still have to put yourself on.”
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8 154 However, as discussed below, she wanted her son to be older before she seriously reconsidered
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0 155 the surgery.

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3 156 The situation was similar for Participant 4, who mentioned that the sale of his business
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5 157 could free him up for the “2-3 month” recovery time post-transplantation. He also mentioned that
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7 158 he and his wife had discussed the possibility of working with another couple on a paired organ
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9 159 exchange strategy: “...I would get a kidney from another [couple], and my wife would give [her
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1 160 kidney to them]...and that way, you get a perfect match, and you can actually schedule when you

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5 161 want to do the transplant.” If these factors could be aligned in the future he seemed open to a
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7 162 transplant.
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10 163 This core category is supported by four sub-categories including *negative past*
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12 164 *experience, feeling well on NHD, gaining autonomy, and responsibility* (see Figure 1). It is
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14 165 noteworthy that these sub-categories are not linear stages wherein the patient’s decision is based
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16 166 on a sequential progression through each stage; rather, they are unique (though perhaps
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18 167 overlapping) factors that influenced the decision made by the participants.
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2 169 **Negative Past Experience**

3 170 Participant experience with transplantation was variable: two had had failed transplants, while
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5 171 the remainder had never received a kidney transplant. The adverse effects of immunosuppression
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7 172 played a significant role in participants’ perceptions of transplantation (rather than
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9 173 transplantation logistics). For example, as Participant 1’s transplant was failing, he described his
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1 174 experience with a round of muromonab-CD3 (the murine monoclonal antibody OKT-3) as
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3 175 follows: “My temperature shot up to 104, 105. I was cooking... just in agony on my bed... I was
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5 176 shaking, I was literally bouncing on the bed.” Participant 2 described side effects associated with
6
7 177 prednisone in the following way: “My feet were just huge; I couldn’t even put shoes on... [and]
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9 178 my blood pressure was extremely high; it was over 200 over 170 or something like that”.

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1 179 While Participant 3 had not experienced a kidney transplant, he received prednisone to
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3 180 treat his underlying kidney disease. He described his experience as follows:
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5 181 [I had] breath that smelled like dead meat...I had a big hump, I started getting acne all
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7 182 over my body...I was bloated and sick...I was also too hot, sweating...And I couldn't
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10 183 sleep. When I did sleep, I would have severe nightmares.

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12 184 Further in relation to participants' concerns with these drugs, Participant 7 (a woman of
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14 185 childbearing age contemplating pregnancy), who post-liver transplantation experienced renal
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16 186 failure from "the toxicity of cyclosporine", wanted "...a guarantee that [the drug is] not going to
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18 187 cross the placenta...I didn't want to have a baby that was sick..."

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21 188 Negative past experience with transplantation was not limited solely to concerns about
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23 189 immunosuppressive drugs. Two participants perceived a mismatch between the medical team's
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25 190 priorities and their own. When describing the loss of his transplant, Participant 2 stated, "I was
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27 191 actually in [the intensive care unit] because the doctor says, 'No, we have to keep this kidney.'
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29 192 So they tried – it didn't seem like the patient was too much of a concern." Furthermore, one of
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31 193 Participant 3's more significant fears, "was to wake up so sick I couldn't even move, and have
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33 194 the doctors patting themselves on the back, looking at all the urine output that my new kidney
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35 195 was producing, and my quality of life was zero."

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37 196 Also under the umbrella of negative experience, participants discussed the drawbacks of
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39 197 undertaking NHD therapy. For Participant 7 there was a financial burden, because "...you have
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41 198 to pay for water and electricity and things of that nature, and damages to the house if you have
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43 199 floods". With respect to the procedure itself, participant 4 noted, "there's a fair bit of prep time
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45 200 for getting the machine ready...". Participant 5 said, "It's like a job; in the beginning you are
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47 201 slow..." Finally, participants lamented that while travelling, they could not bring their NHD
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49 202 equipment with them. Participant 5 also explained, "And I know, because when I do travel, I

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5 203 switch back to conventional, and I notice a *huge* [negative] difference [in energy on conventional
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7 204 dialysis] (emphasis added)".
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11 206 **Feeling Well on NHD**

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14 207 All interview participants had experience with conventional dialysis, and discussed NHD in
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16 208 relation to this alternative modality. Participant 5 stated that on NHD "[you have] more energy.
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18 209 [Your] colour will change; like, you'll look normal". She went on to talk about how differences
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20 210 in pump speed affected her: "the [hospital] machine; it's more aggressive [...], so they do put it
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22 211 at 400 pump speed, so I start to crash [after] about two hours...nocturnal is over 8 hours...so it's
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24 212 much easier on your body."
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31 213 Participants also mentioned that there were fewer food restrictions with the NHD. As
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33 214 Participant 4 described, "...I didn't have any restrictions on food or how much I could drink...so
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35 215 I was pretty free." Participant 6 added that in addition to having no food or drink restrictions,
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37 216 "I've gone off almost all of my medications." Participants 3 and 5 also discussed the need for
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39 217 fewer medications (i.e., darbepoetin alpha, iron, Vitamin D and multi-vitamins).

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41 218 Finally, female participants mentioned normalization of fertility. Both of the female
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43 219 participants had successful pregnancies, without medical complications. As Participant 5
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45 220 described, after being told that her best chance of becoming pregnant was to receive a kidney
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47 221 transplant, "I didn't actually go on the list [for other reasons at the time]. Then I was offered
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49 222 nocturnal dialysis...then something positive happened, and I completely put transplant on the
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51 223 back burner, because I actually conceived..." Participant 7 offered a similar story, saying that,
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5 224 “[the NHD machine] came...and then I went on five times a week, because I was told...it’s the
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7 225 best cleaning...I was married...and [then] I got pregnant...”
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11 227 **Gaining autonomy**

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14 228 Each of the participants also spoke about the value of (re)gaining autonomy. For some, this was
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16 229 about travel. Participant 1 stated, “Well, I can adjust it and do whatever I want. If I need to go on
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18 230 a holiday, [a] 3-day trip or something, I can dialyze before I leave and when I get home...that’s
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21 231 the kind of convenience patients need.” For Participant 2, who was a farmer from a rural
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23 232 community, NHD offered “freedom to do what you have to do during the day. I dialyze at night,
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25 233 and then during the day I can do whatever I need. I don’t have to sit [attached to] the machine for
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27 234 4 1/2 hours.”

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29 235 Participant 6 liked “the fact that, for lack of a better way to put it, I’m my own boss”. For
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31 236 Participant 7, NHD enabled “a bit more control over my health; even though I don’t have that
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33 237 much, it allows me some control over my life...” Participant 3 described the value of having
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35 238 control over his dialysis schedule in the following way:

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37 239 “The biggest issue for me [is] psychological...the worst thing for me now is having to
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39 240 have a procedure...where they tell me I have to go back to the ward at the hospital...I
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41 241 call it the “zombie ward”...many of them [other patients] are essentially furniture being
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43 242 wheeled in and out to dialyze”.

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45 243 Participant 3 went on to say, “That’s the weird thing about home hemo in terms of psychological
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47 244 benefits. I don’t know if everyone feels like this, but you can kind of get to this place where...I
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49 245 don’t really feel sick.” Participant 4 described NHD as, “an alternate to a transplant that you can

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5 246 live a pretty normal life. I travel a fair bit for work, and then we've gone on vacations...and
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7 247 there's never really been any issue with that."
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11 249 **Responsibility**

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14 250 Finally, participants considered their responsibility to their families when making their treatment
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16 251 decisions. Participant 1's marriage was seriously tested during his kidney transplant. He
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18 252 reported, "My wife's visiting me [in hospital] after work every day, seeing the crap I'm going
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21 253 through...She was alone... she had nobody..." As described earlier, Participant 7 considered
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23 254 transplantation, but wanted to maintain the status quo: "my son's 8; I want him to be a bit older,
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25 255 simply because I want him to be able to take care of himself". Participant 7 was also the primary
26
27 256 income earner in her family, so taking time away from work to have a transplant was a low
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29 257 priority. Participant 3, who was a full-time student in a competitive professional program, said,
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31 258 "if I had to do a cadaveric transplant, I'd probably have to give up [school], because I don't see
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33 259 myself continuing on with it if I have to take another year off...I need to get working for the sake
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35 260 of my family."
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39 263 **DISCUSSION:**

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41 264 In this grounded theory study the core category of "why take a chance when things are going
42
43 265 well?" was identified. All participants indicated that their experience with NHD provided them
44
45 266 with a good quality of life and the trade-offs of potential adverse events with transplantation,
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47 267 including medical, psychological and social factors, were not worth the risk. This interplay of
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49 268 trade-offs was informed by four sub-categories including "past negative experience", "feeling
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5 268 well on NHD”, “gaining autonomy”, and “responsibility”, which illustrate both how patients
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7 269 evaluated their current condition, and how they made decisions to accommodate their individual
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10 270 priorities.

11 271 While much has been written about patient and caregiver decision-making regarding
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13 272 treatment options in chronic kidney disease generally,[16] there is a paucity of literature
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15 273 surrounding patient decision-making when choosing to forgo transplantation specifically. The
16
17 274 only study to address this question directly reports on cross-sectional survey results of 57
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19 275 Slovenian conventional hemodialysis patients who opted to remain on dialysis.[17] In this study,
20
21 276 the 3 most common reasons given for forgoing transplantation were fear of immunosuppressive
22
23 277 medication side-effects (31%), the perception that “transplantation is a lottery” (i.e., transplant
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25 278 outcomes were unpredictable) (30%), and patients’ knowledge of peers whose general medical
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27 279 condition had deteriorated following a kidney transplant (29%).[17]

28 280 Many of the factors influencing patient decision-making around transplantation in this
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30 281 study have been echoed in patient choice of a dialysis treatment option. A recent systematic
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32 282 review of ESRD patients’ decision-making choices found that decisions were impacted by the
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34 283 experiences of peers, the timing of the information being provided by health care professionals,
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36 284 and a desire by patients to maintain the status quo.[16] The current study support these
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38 285 observations, though none of our participants identified adverse outcomes of other dialysis
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40 286 patients as influencing their own decisions. This may relate to the lack of generalizability of
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42 287 studies informing the systematic review to the younger, highly functioning and independent
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44 288 NHD patients in our sample, who have limited contact with other ESRD patients because they
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46 289 dialyze at home.

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5 290 Furthermore, the objectives of previous studies focused on individual factors'
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7 291 independent contribution to patients' decisions without connecting them to a larger framework
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10 292 relating to the decision-making process, as we have done in the current study. This previous
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12 293 work has largely neglected the social factors including patients' families and employment status,
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14 294 which we found integral to participants' decision-making. Not surprisingly, patients who were
15
16 295 working, active and mobile are "most likely to be involved their own care and decision
17
18 296 making".[18] The current study builds on previous literature and proposes a unifying framework
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20
21 297 for the basic social process underlying patients' decisions to forgo transplantation and remain on
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23 298 NHD.
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300 **Limitations**

301 This study has a number of limitations. The sample size, though adequate for a qualitative study,
302 was small and limited to the Canadian health care setting. Participants are not necessarily
303 representative of the broader population of NHD patients. Furthermore, since patient
304 perspectives on NHD and transplantation are presumably influenced by their previous experience
305 with conventional hemo- or peritoneal dialysis, the opinions expressed by participants in the
306 current study may differ from the small, but increasing proportion of incident ESRD patients
307 who have only ever received NHD. Nevertheless, this is the first study in which the factors
308 contributing to decision-making of NHD patients to decline transplantation has been
309 systematically explored.

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5 311 Currently, there is no evidence to support the optimal treatment choice in patients undergoing
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7 312 NHD who do not wish to be transplanted. Hence, it is important that patients recognize they have
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10 313 a choice regarding treatment, and that health professionals understand how and why patients
11
12 314 make decisions regarding modality. This research underscores that a patient-centered approach to
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14 315 decision-making about treatment is critical. This study: 1) provides insight into patients' thought
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16 316 processes surrounding an important treatment decision, 2) allows the renal team to better
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18 317 understand, and thereby respect, patient choice in a patient-centered care paradigm, and 3) may
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21 318 help to identify opportunities for educational interventions of patients' understanding of
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23 319 anticipated risks and benefits of various treatment options. It is important that health care
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25 320 providers listen carefully to stories about patients' past experiences, and ask about their future
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27 321 expectations, in order to help them make the best decisions.
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5 324 **CONTRIBUTORSHIP STATEMENT:**

6
7 325 Research idea and study design: MR, AM, RP; data acquisition: MR; data analysis/interpretation:
8
9 326 MR, AM, SC, JK, CC, RP; statistical analysis: NOT APPLICABLE; supervision or mentorship:
10
11 327 RP and CT; drafting and final approval of manuscript: MR, AM, SC, JK, CC, RP. Each author
12
13 328 contributed important intellectual content during manuscript drafting or revision and accepts
14
15 329 accountability for the overall work by ensuring that questions pertaining to the accuracy or
16
17 330 integrity of any portion of the work are appropriately investigated and resolved. MR takes
18
19 331 responsibility that this study has been reported honestly, accurately, and transparently; that no
20
21 332 important aspects of the study have been omitted; and that any discrepancies from the study as
22
23 333 planned (and, if relevant, registered) have been explained.
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36
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38
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40
41 338 with patient recruitment and consenting. The authors would also like to acknowledge the
42
43 339 important contributions of the patients who agreed to participate in this study.
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55 342 **COMPETING INTERESTS:**

56 343 We have read and understood BMJ policy on declaration of interests and declare that we have no
57
58 344 competing interests.
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10 349 interpretation of data; writing the report; and the decision to submit the report for publication.
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14 351 **DATA SHARING STATEMENT:**

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16 352 No additional data is available.

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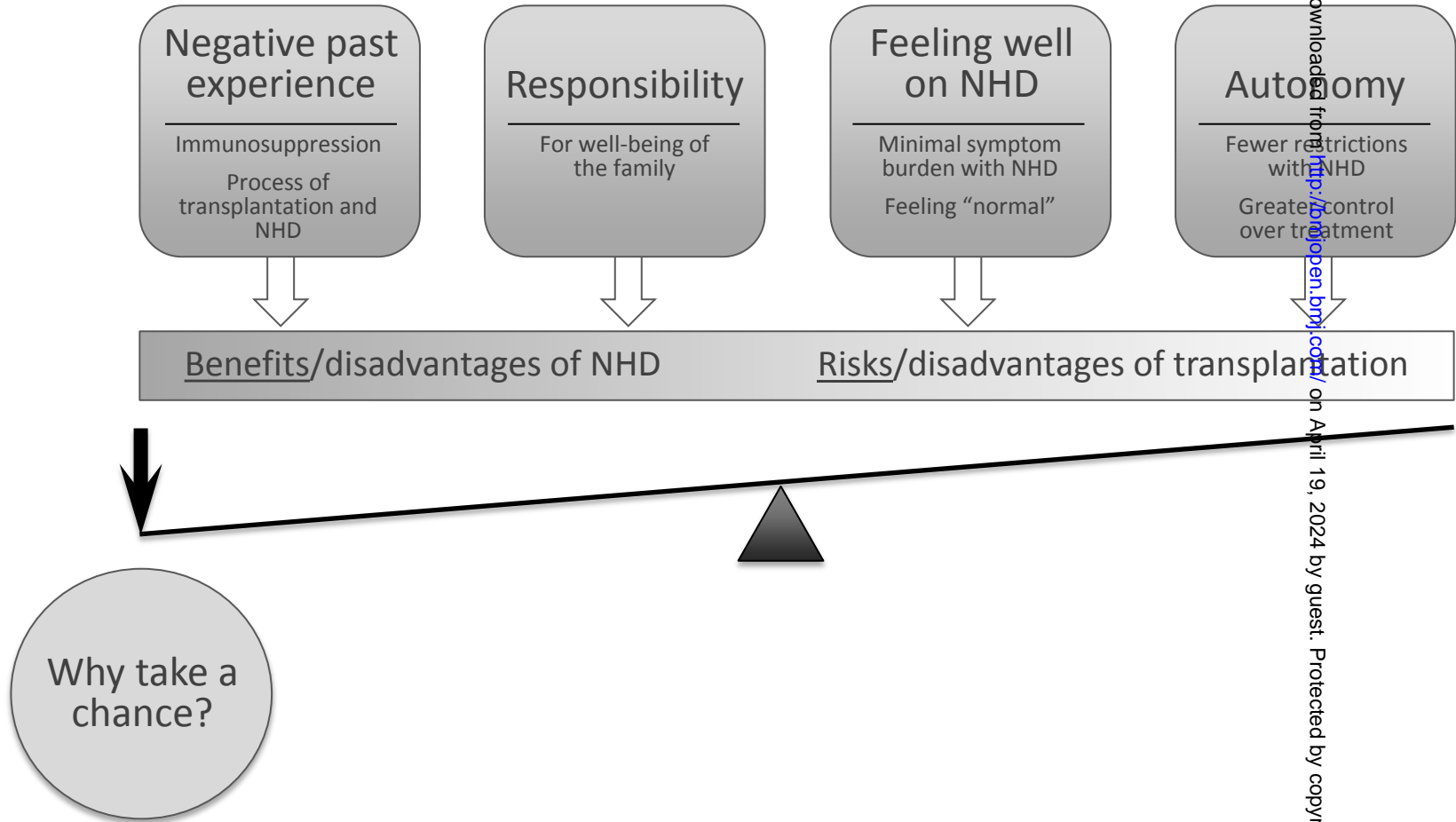
407 **FIGURE LEGEND:**

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409 Figure 1 – The core category “Why take a chance when things are going well” was identified. The perceptions of risks and benefits
410 of NHD versus transplantation were informed by 4 sub-categories that appear to be independent though not necessarily mutually
411 exclusive.

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BMJ Open

WHY TAKE THE CHANCE?: A QUALITATIVE GROUNDED THEORY STUDY OF NOCTURNAL HEMODIALYSIS RECIPIENTS WHO DECLINE KIDNEY TRANSPLANTATION

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WHY TAKE THE CHANCE?: A QUALITATIVE GROUNDED THEORY STUDY OF
NOCTURNAL HEMODIALYSIS RECIPIENTS WHO DECLINE KIDNEY
TRANSPLANTATION

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KEY WORDS: Decision making, grounded theory, nocturnal hemodialysis, transplantation

WORD COUNT: 2998

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5 27 **ABSTRACT:**
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7 28
8 29 **Objective:** The objective of this study was to examine the factors that influence decision-making
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10 30 to forgo transplantation in favor of remaining on nocturnal hemodialysis (NHD).
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16 32 **Design:** A grounded theory approach using in-depth telephone interviewing was used.
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21 34 **Setting:** Participants were identified from two tertiary care renal programs in Canada.
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27 36 **Participants:** The study participants were otherwise eligible end stage renal disease (ESRD)
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29 37 patients who have opted to remain off of the transplant list. A total of seven eligible participants
30
31 38 were interviewed. Five were male. The mean age was 46 years.
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37 40 **Analysis:** A constant comparative method of analysis was used to identify a core category and
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39 41 factors influencing the decision-making process.
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43 43 **Results:** In this grounded theory study of people receiving NHD who refused kidney
44
45 44 transplantation, the core category of “why take a chance when things are going well?” was
46
47 45 identified, along with four factors that influenced the decision including “negative past
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49 46 experience”, “feeling well on NHD”, “gaining autonomy”, and “responsibility”.
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5 48 **Conclusions:** This study provides insight into patients' thought processes surrounding an
6
7 49 important treatment decision. Such insights might help the renal team to better understand, and
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10 50 thereby respect, patient choice in a patient-centered care paradigm. Findings may also be useful
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12 51 in the development of education programs addressing the specific concerns of this population of
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14 52 patients.
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19 54 **STRENGTHS AND LIMITATIONS OF THIS STUDY:**

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21 55
- 22 • The use of grounded theory allowed for the development of a testable theory for
23 understanding patient decision-making.
24 56
 - 25 • Interviews enable an in-depth and detailed examination of patients' experience.
26 57
 - 27 • The rarity of this phenomenon made obtaining a large sample difficult.
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 - 29 • All participants undertook traditional dialysis modalities prior to starting NHD; therefore
30 59 their experiences may not be representative of patients who have only even done NHD.
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63 INTRODUCTION:

64 The emergence of nocturnal home hemodialysis (NHD) in the mid 1990s was seen as a
65 welcome addition to ESRD treatment options.[1] NHD is typically self-administered 4-6 nights
66 per week, while the patient sleeps, with each treatment lasting 7-9 hours.[2] By increasing the
67 frequency and duration of dialysis, this treatment improves markers of mineral metabolism,
68 reduces dependence on antihypertensive medications, liberalizes dietary restrictions, and results
69 in better health-related quality of life when compared to conventional hemodialysis.[3] Evidence
70 suggests that this intensive dialysis provides superior patient survival compared to conventional
71 hemodialysis, perhaps similar to deceased donor transplantation.[2, 4, 5, 6] Notwithstanding
72 these observations, clinicians appropriately continue to advocate for transplantation for all
73 suitable candidates,[7] since kidney transplantation is generally regarded as the gold standard
74 treatment for those with end-stage renal disease (ESRD).[8-11]

75 An environmental scan of two large well-established home hemodialysis programs in
76 Canada reveals that approximately 15% of transplantable patients on NHD choose to forgo the
77 gold standard treatment, despite being otherwise medically eligible. This is often against the
78 advice of their care team. It is not currently known why patients choose to remain on NHD when
79 a presumably better treatment is available. Hence, the objective of this study was to examine the
80 factors that influence decision-making to forgo transplantation in favor of remaining on NHD.

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82 SUBJECTS and METHODS:

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84 Design:

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5 85 A qualitative study design, applying grounded theory, was selected to enable the description and
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7 86 exploration of the basic social process leading to the decision to decline transplantation.[12]
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10 87 Grounded theory supports theory development through the identification of core categories.[13]
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15 89 **Sample and sampling:**

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18 90 We selected a purposive sample of NHD recipients who declined transplantation. Patients were
19
20 91 recruited from two home hemodialysis programs: the Northern Alberta Renal Program (NARP)
21
22 92 and the Toronto General Hospital – University Health Network. Patients were eligible if they
23
24 93 were over 18 years of age, English-speaking, had received NHD for at least 3 months, and
25
26 94 declined wait listing for kidney transplantation. Patients were excluded if they were not eligible
27
28 95 to be transplanted for any reason (e.g., prohibitive comorbid conditions). All participants
29
30 96 provided written informed consent to a third party not otherwise involved with this study, or
31
32 97 patient care. Ethics approval was obtained from the Health Research Ethics Boards at the
33
34 98 University of Alberta and the University of Toronto. The research activities being reported are
35
36 99 consistent with the Principles of the Declaration of Istanbul.
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44 101 **Data collection:**

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47 102 Semi-structured telephone interviews were conducted with each participant because of the wide
48
49 103 geographic distribution of the participants. Telephone interviewing has been validated in
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51 104 qualitative research to obtain rich descriptions about sensitive topics.[14] All interviews were
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53 105 conducted by MR, who was trained and experienced in conducting such interviews, and who had
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5 106 no prior relationship with study participants. Interviews started with open-ended questions
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7 107 regarding participants' experiences with NHD, and perceptions of transplantation, followed by
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10 108 more detailed and probing questions depending on responses. Interviews lasted 20 minutes to 2.5
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12 109 hours (median time of 30 minutes). All interviews were audio-recorded and transcribed verbatim.
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14 110 Field notes were recorded for each interview.

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17 111 Baseline clinical information was collected by chart review. This included demographic
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19 112 data, comorbidities, dialysis prescription, and measures of routine laboratory variables. These
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21 113 data were used to verify participants' eligibility for kidney transplantation by two independent
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23 114 transplant nephrologists (SC and JK).

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29 116 **Analysis:**

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32 117 A constant comparative approach, wherein every piece of data was compared to other pieces of
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34 118 data was used to identify common themes and a core category.[15] Research team members MR,
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36 119 AM, and RP, independently examined and coded the interview transcripts, and met on three
37
38 120 separate occasions, two of which were during the active data collection phase, to discuss
39
40 121 interview findings (MR is qualitative methods expert, AM is an experienced qualitative
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42 122 nephrology researcher, and RP is a clinician nephrologist/epidemiologist). This approach
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44 123 resulted in refinement of future interview questions to probe participants about subjects raised by
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46 124 previous participants and added depth to the interviews. Data collection continued until no new
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48 125 findings or themes emerged (i.e., saturation).

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127 **RESULTS:**

128 A total of seven participants were interviewed; five were male. The mean age was 46 years
 129 (range 39-55). Six of the participants were employed; the seventh was a full-time student. Each
 130 had been on NHD for at least one year, with some using this therapy for more than 10 years.
 131 More detailed participant characteristics are summarized in Table 1.

133 Table 1 – Participant characteristics¹

	Participants						
	1	2	3	4	5	6	7
Years with ESRD	23	14	5	14	12	11	12
Years on NHD	6	1	1	11	11	8	9
Nights per week of NHD	4	5	3	5	6	4	5
Hours per night of NHD	8	7.5	9	8	7.5	8	8
History of cancer	No	Yes ²	No	Yes ²	No	No	Yes ²
History of ischemic heart disease	No	No	No	No	No	No	No
BMI (kg/m ²)	26.2	31.5	29.7	28	26.2	24.4	20.1
Albumin (g/dL)	44	36	43	40	33	38	38
Calcium (mg/dL)	2.66	2.28	2.71	2.62	2.31	2.25	2.55
Phosphate (mg.dL)	2.06	1.10	1.57	2.49	1.36	1.51	0.93
Hemoglobin (g/dL)	103	98	133	121	119	138	108
Antihypertensive drug use	No	No	No	Yes	No	Yes	No

134 ¹ Respondent characteristics including age, gender, race, underlying disease, previous transplant history, and current
 135 employment status have not been included in this table to comply with norms in the publication of qualitative
 136 research designed to maintain confidentiality.[16]

137 ² Respondent was cancer free at the time of decision re: transplant

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5 139 The following sections outline the interview findings beginning with an overview of the
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7 140 core category, “why take a chance when things are going well?”, and a description of the
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9 141 medical, psychological, and social factors contributing to this category.
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12 142

14 143 **Why Take a Chance when Things are Going Well?**

16
17 144 This category reflected participants’ active assessment and weighing of the medical and social
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19 145 risks/benefits of the therapy in question prior to making a decision. Overall, participants reported
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21 146 general satisfaction with their current health and circumstances. Each participant discussed being
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23 147 able to pursue activities important to her or him, including having children and traveling, and did
24
25 148 not feel limited by their health condition.

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28 149 While at the time of the interviews, none of the participants was actively pursuing
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30 150 transplantation; it was also evident that this decision may change if circumstances changed. For
31
32 151 example, Participant 7 mused about having a transplant in the future and stated, “if it
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34 152 [transplantation] gives me 10, 15 years without the machine, I’ll be 55-ish...’cause even though
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36 153 having it [dialysis] at home is great, but it’s still a machine, you still have to put yourself on.”
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38 154 However, as discussed below, she wanted her son to be older before she seriously reconsidered
39
40 155 the surgery.

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43 156 The situation was similar for Participant 4, who mentioned that the sale of his business
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45 157 could free him up for the “2-3 month” recovery time post-transplantation. He also mentioned that
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47 158 he and his wife had discussed the possibility of working with another couple on a paired organ
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49 159 exchange strategy: “...I would get a kidney from another [couple], and my wife would give [her
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51 160 kidney to them]...and that way, you get a perfect match, and you can actually schedule when you
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5 161 want to do the transplant.” If these factors could be aligned in the future he seemed open to a
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7 162 transplant.
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10 163 This core category is supported by four sub-categories including *negative past*
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12 164 *experience, feeling well on NHD, gaining autonomy, and responsibility* (see Figure 1). It is
13
14 165 noteworthy that these sub-categories are not linear stages wherein the patient’s decision is based
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16 166 on a sequential progression through each stage; rather, they are unique (though perhaps
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18 167 overlapping) factors that influenced the decision made by the participants.
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22 23 24 169 **Negative Past Experience**

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26 170 Participant experience with transplantation was variable: two had had failed transplants, while
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28 171 the remainder had never received a kidney transplant. The adverse effects of immunosuppression
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30 172 played a significant role in participants’ perceptions of transplantation (rather than
31
32 173 transplantation logistics). For example, as Participant 1’s transplant was failing, he described his
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34 174 experience with a round of muromonab-CD3 (the murine monoclonal antibody OKT-3) as
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36 175 follows: “My temperature shot up to 104, 105. I was cooking... just in agony on my bed... I was
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38 176 shaking, I was literally bouncing on the bed.” Participant 2 described side effects associated with
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40 177 prednisone in the following way: “My feet were just huge; I couldn’t even put shoes on... [and]
41
42 178 my blood pressure was extremely high; it was over 200 over 170 or something like that”.

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47 179 While Participant 3 had not experienced a kidney transplant, he received prednisone to
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49 180 treat his underlying kidney disease. He described his experience as follows:
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5 181 [I had] breath that smelled like dead meat...I had a big hump, I started getting acne all
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7 182 over my body...I was bloated and sick...I was also too hot, sweating...And I couldn't
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10 183 sleep. When I did sleep, I would have severe nightmares.

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12 184 Further in relation to participants' concerns with these drugs, Participant 7 (a woman of
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14 185 childbearing age contemplating pregnancy), who post-liver transplantation experienced renal
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16 186 failure from "the toxicity of cyclosporine", wanted "...a guarantee that [the drug is] not going to
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18 187 cross the placenta...I didn't want to have a baby that was sick...."

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21 188 Negative past experience with transplantation was not limited solely to concerns about
22
23 189 immunosuppressive drugs. Two participants perceived a mismatch between the medical team's
24
25 190 priorities and their own. When describing the loss of his transplant, Participant 2 stated, "I was
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27 191 actually in [the intensive care unit] because the doctor says, 'No, we have to keep this kidney.'
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29 192 So they tried – it didn't seem like the patient was too much of a concern." Furthermore, one of
30
31 193 Participant 3's more significant fears, "was to wake up so sick I couldn't even move, and have
32
33 194 the doctors patting themselves on the back, looking at all the urine output that my new kidney
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35 195 was producing, and my quality of life was zero."

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38 196 Also under the umbrella of negative experience, participants discussed the drawbacks of
39
40 197 undertaking NHD therapy. For Participant 7 there was a financial burden, because "...you have
41
42 198 to pay for water and electricity and things of that nature, and damages to the house if you have
43
44 199 floods". With respect to the procedure itself, participant 4 noted, "there's a fair bit of prep time
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46 200 for getting the machine ready...". Participant 5 said, "It's like a job; in the beginning you are
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48 201 slow..." Finally, participants lamented that while travelling, they could not bring their NHD
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50 202 equipment with them. Participant 5 also explained, "And I know, because when I do travel, I
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5 203 switch back to conventional, and I notice a *huge* [negative] difference [in energy on conventional
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7 204 dialysis] (emphasis added)".
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11 206 **Feeling Well on NHD**

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14 207 All interview participants had experience with conventional dialysis, and discussed NHD in
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17 208 relation to this alternative modality. Participant 5 stated that on NHD "[you have] more energy.
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19 209 [Your] colour will change; like, you'll look normal". She went on to talk about how differences
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21 210 in pump speed affected her: "the [hospital] machine; it's more aggressive [...], so they do put it
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24 211 at 400 pump speed, so I start to crash [after] about two hours...nocturnal is over 8 hours...so it's
25
26 212 much easier on your body."
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29 213 Participants also mentioned that there were fewer food restrictions with the NHD. As
30
31 214 Participant 4 described, "...I didn't have any restrictions on food or how much I could drink...so
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33 215 I was pretty free." Participant 6 added that in addition to having no food or drink restrictions,
34
35 216 "I've gone off almost all of my medications." Participants 3 and 5 also discussed the need for
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37
38 217 fewer medications (i.e., darbepoetin alpha, iron, Vitamin D and multi-vitamins).
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40 218 Finally, female participants mentioned normalization of fertility. Both of the female
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43 219 participants had successful pregnancies, without medical complications. As Participant 5
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45 220 described, after being told that her best chance of becoming pregnant was to receive a kidney
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47 221 transplant, "I didn't actually go on the list [for other reasons at the time]. Then I was offered
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50 222 nocturnal dialysis...then something positive happened, and I completely put transplant on the
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52 223 back burner, because I actually conceived..." Participant 7 offered a similar story, saying that,
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5 224 “[the NHD machine] came...and then I went on five times a week, because I was told...it’s the
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7 225 best cleaning...I was married...and [then] I got pregnant...”
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11 227 **Gaining autonomy**

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14 228 Each of the participants also spoke about the value of (re)gaining autonomy. For some, this was
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16
17 229 about travel. Participant 1 stated, “Well, I can adjust it and do whatever I want. If I need to go on
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19 230 a holiday, [a] 3-day trip or something, I can dialyze before I leave and when I get home...that’s
20
21 231 the kind of convenience patients need.” For Participant 2, who was a farmer from a rural
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23
24 232 community, NHD offered “freedom to do what you have to do during the day. I dialyze at night,
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26 233 and then during the day I can do whatever I need. I don’t have to sit [attached to] the machine for
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28 234 4 1/2 hours.”

29
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31 235 Participant 6 liked “the fact that, for lack of a better way to put it, I’m my own boss”. For
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33 236 Participant 7, NHD enabled “a bit more control over my health; even though I don’t have that
34
35 237 much, it allows me some control over my life...” Participant 3 described the value of having
36
37 238 control over his dialysis schedule in the following way:

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40 239 “The biggest issue for me [is] psychological...the worst thing for me now is having to
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42 240 have a procedure...where they tell me I have to go back to the ward at the hospital...I
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44 241 call it the “zombie ward”...many of them [other patients] are essentially furniture being
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46 242 wheeled in and out to dialyze”.

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49 243 Participant 3 went on to say, “That’s the weird thing about home hemo in terms of psychological
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51 244 benefits. I don’t know if everyone feels like this, but you can kind of get to this place where...I
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54 245 don’t really feel sick.” Participant 4 described NHD as, “an alternate to a transplant that you can
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5 246 live a pretty normal life. I travel a fair bit for work, and then we've gone on vacations...and
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7 247 there's never really been any issue with that."
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11 249 **Responsibility**

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14 250 Finally, participants considered their responsibility to their families when making their treatment
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16 251 decisions. Participant 1's marriage was seriously tested during his kidney transplant. He
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18 252 reported, "My wife's visiting me [in hospital] after work every day, seeing the crap I'm going
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20 253 through...She was alone... she had nobody..." As described earlier, Participant 7 considered
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22 254 transplantation, but wanted to maintain the status quo: "my son's 8; I want him to be a bit older,
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24 255 simply because I want him to be able to take care of himself". Participant 7 was also the primary
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26 256 income earner in her family, so taking time away from work to have a transplant was a low
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28 257 priority. Participant 3, who was a full-time student in a competitive professional program, said,
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30 258 "if I had to do a cadaveric transplant, I'd probably have to give up [school], because I don't see
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32 259 myself continuing on with it if I have to take another year off...I need to get working for the sake
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34 260 of my family."
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41 262 **DISCUSSION:**

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44 263 In this grounded theory study the core category of "why take a chance when things are going
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46 264 well?" was identified. All participants indicated that their experience with NHD provided them
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48 265 with a good quality of life and the trade-offs of potential adverse events with transplantation,
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50 266 including medical, psychological and social factors, were not worth the risk. This interplay of
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52 267 trade-offs was informed by four sub-categories including "past negative experience", "feeling
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5 268 well on NHD”, “gaining autonomy”, and “responsibility”, which illustrate both how patients
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7 269 evaluated their current condition, and how they made decisions to accommodate their individual
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10 270 priorities.

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12 271 While much has been written about patient and caregiver decision-making regarding
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14 272 treatment options in chronic kidney disease generally,[17] there is a paucity of literature
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17 273 surrounding patient decision-making when choosing to forgo transplantation specifically. The
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19 274 only study to address this question directly reports on cross-sectional survey results of 57
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21 275 Slovenian conventional hemodialysis patients who opted to remain on dialysis.[17] In this study,
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23
24 276 the 3 most common reasons given for forgoing transplantation were fear of immunosuppressive
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26 277 medication side-effects (31%), the perception that “transplantation is a lottery” (i.e., transplant
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28 278 outcomes were unpredictable) (30%), and patients’ knowledge of peers whose general medical
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31 279 condition had deteriorated following a kidney transplant (29%).[18]

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33 280 Many of the factors influencing patient decision-making around transplantation in this
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36 281 study have been echoed in patient choice of a dialysis treatment option. A recent systematic
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38 282 review of ESRD patients’ decision-making choices found that decisions were impacted by the
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40 283 experiences of peers, the timing of the information being provided by health care professionals,
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42 284 and a desire by patients to maintain the status quo.[17] The current study support these
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45 285 observations, though none of our participants identified adverse outcomes of other dialysis
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47 286 patients as influencing their own decisions. This may relate to the lack of generalizability of
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50 287 studies informing the systematic review to the younger, highly functioning and independent
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52 288 NHD patients in our sample, who have limited contact with other ESRD patients because they
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55 289 dialyze at home.

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5 290 Furthermore, the objectives of previous studies focused on individual factors'
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7 291 independent contribution to patients' decisions without connecting them to a larger framework
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10 292 relating to the decision-making process, as we have done in the current study. While this is
11
12 293 beginning to change with the completion of new qualitative studies,[19] previous work has
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14 294 largely neglected the social factors including patients' families and employment status, which we
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16 295 found integral to participants' decision-making. Not surprisingly, patients who were working,
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18 296 active and mobile are "most likely to be involved their own care and decision making".[20] The
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21 297 current study builds on previous literature and proposes a unifying framework for the basic social
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23 298 process underlying patients' decisions to forgo transplantation and remain on NHD.
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27 28 300 **Limitations**

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31 301 This study has a number of limitations. The sample size, though adequate for a qualitative study,
32
33 302 was small and limited to the Canadian health care setting. Participants are not necessarily
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35 303 representative of the broader population of NHD patients. Furthermore, since patient
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37 304 perspectives on NHD and transplantation are presumably influenced by their previous experience
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39 305 with conventional hemo- or peritoneal dialysis, the opinions expressed by participants in the
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41 306 current study may differ from the small, but increasing proportion of incident ESRD patients
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43 307 who have only ever received NHD. Nevertheless, this is the first study in which the factors
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45 308 contributing to decision-making of NHD patients to decline transplantation has been
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47 309 systematically explored.
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5 311 Currently, there is no evidence to support the optimal treatment choice in patients undergoing
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7 312 NHD who do not wish to be transplanted. Hence, it is important that patients recognize they have
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9 313 a choice regarding treatment, and that health professionals understand how and why patients
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11 314 make decisions regarding modality. This research underscores that a patient-centered approach to
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13 315 decision-making about treatment is critical. This study: 1) provides insight into patients' thought
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15 316 processes surrounding an important treatment decision, 2) allows the renal team to better
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17 317 understand, and thereby respect, patient choice in a patient-centered care paradigm, and 3) may
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19 318 help to identify opportunities for educational interventions of patients' understanding of
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21 319 anticipated risks and benefits of various treatment options. It is important that health care
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23 320 providers listen carefully to stories about patients' past experiences, and ask about their future
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25 321 expectations, in order to help them make the best decisions.
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5 324 **CONTRIBUTORSHIP STATEMENT:**
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7 325 Research idea and study design: MR, AM, RP; data acquisition: MR; data analysis/interpretation:
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9 326 MR, AM, SC, JK, CC, RP; statistical analysis: NOT APPLICABLE; supervision or mentorship:
10
11 327 RP and CT; drafting and final approval of manuscript: MR, AM, SC, JK, CC, RP. Each author
12
13 328 contributed important intellectual content during manuscript drafting or revision and accepts
14
15 329 accountability for the overall work by ensuring that questions pertaining to the accuracy or
16
17 330 integrity of any portion of the work are appropriately investigated and resolved. MR takes
18
19 331 responsibility that this study has been reported honestly, accurately, and transparently; that no
20
21 332 important aspects of the study have been omitted; and that any discrepancies from the study as
22
23 333 planned (and, if relevant, registered) have been explained.
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32
33 336 Research Coordinator, of the Department of Nephrology, University of Alberta, and Margaret
34
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36
37 338 with patient recruitment and consenting. The authors would also like to acknowledge the
38
39 339 important contributions of the patients who agreed to participate in this study.
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46 342 **COMPETING INTERESTS:**
47

48 343 We have read and understood BMJ policy on declaration of interests and declare that we have no
49
50 344 competing interests.
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6
7 348 is available. The study sponsor had no role in study design; collection, analysis, and
8
9 349 interpretation of data; writing the report; and the decision to submit the report for publication.
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14 351 **DATA SHARING STATEMENT:**

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16 352 No additional data is available.

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411 **FIGURE LEGEND:**

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413 Figure 1 – The core category “Why take a chance when things are going well” was identified. The perceptions of risks and benefits
414 of NHD versus transplantation were informed by 4 sub-categories that appear to be independent though not necessarily mutually
415 exclusive.

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Figure 1

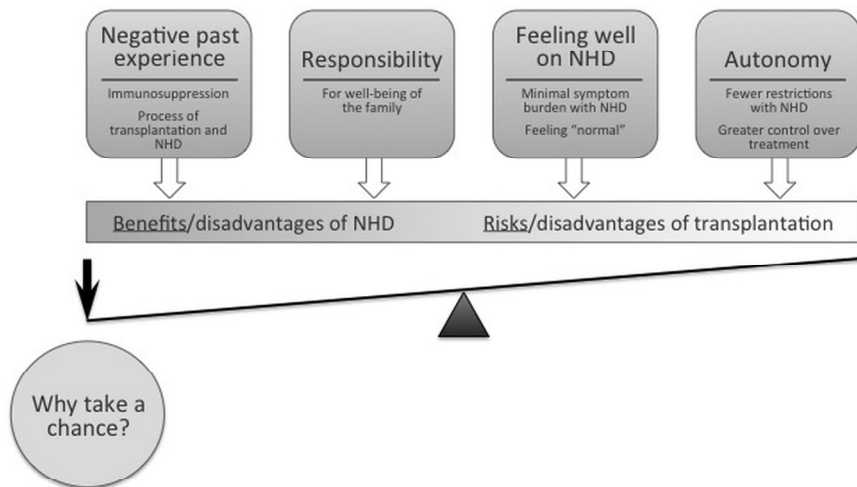


Figure 1 – The core category “Why take a chance when things are going well” was identified. The perceptions of risks and benefits of NHD versus transplantation were informed by 4 sub-categories that appear to be independent though not necessarily mutually exclusive.
254x190mm (300 x 300 DPI)

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist*	
	Author responses
Domain 1: Research team and reflexivity	
<i>Personal Characteristics</i>	
1. Interviewer/facilitator	Meagen Rosenthal (MR) - pg. 1
2. Credentials	PhD- pg. 1
3. Occupation	Assistant professor- pg. 1
4. Gender	Female
5. Experience and training	MA in sociology, PhD in experimental medicine, with a focus on qualitative data collection and analysis - pg. 5-6
<i>Relationship with participants</i>	
6. Relationship established	No relationship between interviewer and participants prior to interview - 5 pg.
7. Participant knowledge of the interviewer	Participants knew that MR would be contacting them to complete and interview, and that she was a qualitative methods researcher - pg. 5-6
8. Interviewer characteristics	None reported outside of MR's background and training - 5-6
Domain 2: study design	
<i>Theoretical framework</i>	
9. Methodological orientation and theory	Grounded theory - 5-6
<i>Participant selection</i>	
10. Sampling	Purposive sample of people with ESRD being treated with NHD, but who had declined Tx - pg. 5
11. Method of approach	Participants were approached by local research staff at each of the programs and asked if they would be willing to participate - pg. 5

12. Sample size	7 - pg. 7
13. Non-participation	0
<i>Setting</i>	
14. Setting of data collection	Interviews were conducted over the telephone - pg. 5-6
15. Presence of non-participants	No non-participants were present during the interviews - pg. 5-6
16. Description of sample	See Table 1 in manuscript - pg. 7
<i>Data collection</i>	
17. Interview guide	Attached
18. Repeat interviews	None
19. Audio/visual recording	Audio recorded - pg. 6
20. Field notes	Yes
21. Duration	20 minutes to 2.5 hours - pg. 6
22. Data saturation	Yes
23. Transcripts returned	No transcripts were returned to participants
Domain 3: analysis and findings Data analysis	
<i>Data analysis</i>	
24. Number of data coders	3 - pg. 6
25. Description of the coding tree	See analysis section of manuscript for description of coding procedures - pg. 6
26. Derivation of themes	See analysis section of manuscript for description of coding procedures- pg. 6
27. Software	No software was used
28. Participant checking	No participant checking was completed
<i>Reporting</i>	
29. Quotations presented	Participant quotations were used and identified - pg. 7-13
30. Data and findings consistent	Yes

1 2 3 4 5	31. Clarity of major themes	Yes
6 7 8	32. Clarity of minor themes	Yes
9		
10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26	*Adapted from: Tong, A., Sainsbury, P. and Craig, J., 2007. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care, 19(6), p.349.	