Paving the Way: A Grounded Theory of Discovery and Decision Making for Individuals With the *CDH1* Marker

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PURPOSE: To understand the process of discovery and decision making for adults with the *CDH1* marker for hereditary diffuse gastric cancer and inherited breast cancer.

PARTICIPANTS & SETTING: Purposeful sampling included 20 participants: 17 adults (11 women and 6 men aged 23–77 years) recruited through the No Stomach for Cancer organization and 3 healthcare providers. Six participants were interviewed two times. Nineteen interviews were done via telephone, and one was conducted in person.

METHODOLOGIC APPROACH: Grounded theory with constant comparison was used.

FINDINGS: The decision-making process of Paving the Way addresses the challenges for individuals diagnosed with the *CDH1* marker. The theory explains the process of learning the risk, discerning testing, choosing iterative individual interventions, and adjusting postoperatively while normalizing to live longer.

IMPLICATIONS FOR NURSING: The process explains and describes the nine factors for decision making and predicts the timing for nursing interventions for genetic testing and pre- and postoperative assessment and planning.

KEYWORDS *CDH1*; grounded theory; genetics; gastric cancer; breast cancer
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Stomach cancer is the fifth leading cause of cancer worldwide, with 1,033,701 estimated new cases and 782,685 deaths reported in 2018 (Bray et al., 2018). The survival rate is particularly poor (4%) for those diagnosed with advanced disease (No Stomach for Cancer [NSFC], 2019; Pernot et al., 2015). Inherited forms of gastrointestinal cancer occur in about 1%–3% of adults. Hereditary diffuse gastric cancer (HDGC) is a rare and difficult-to-detect form of gastrointestinal cancer with a very poor prognosis (van der Post et al., 2015). HDGC is a germline (inheritable) cell-to-cell adhesion protein E-cadherin gene—known as *CDH1*—first discovered by a team of researchers within a native Māori family in New Zealand (Guilford et al., 1999) and since identified in Europe, Canada, and the United States (Corso et al., 2012). Although gastric cancer risk is higher in the Asian population, the incidence of a germline diffuse gastric cancer is low and seen more frequently in individuals of European descent (Sugimoto et al., 2015). The risk of developing HDGC for *CDH1*-positive individuals is 70% (95% confidence interval [CI] [59, 80]) for men by age 80 years and 56% (95% CI [44, 69]) for women; in addition, women have a 42% (95% CI [23, 68]) risk for lobular breast cancer (BC) (Kaurah & Huntsman, 2018; Kaurah et al., 2010). Statistical data for *CDH1*-related male BC remains undetermined. The average age of HDGC at diagnosis is 38 years; however, it can occur in adolescents and adults aged 14–69 years (Hansford et al., 2015; van der Post et al., 2015). Detection of HDGC is difficult because of the insidious tumor growth, which begins underneath the lining of the stomach in poorly differentiated signet ring cell cancer (Onitilo et al., 2013; Pernot et al., 2015), and the lack of observable presenting symptoms in patients (Hebbard et al., 2009; Mastoraki et al., 2011; van der Post et al., 2015).