



## Illness uncertainty in breast cancer patients: Validation of the 5-item short form of the Mishel Uncertainty in Illness Scale



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### A B S T R A C T

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Information

**Purpose:** Several studies have shown that uncertainty about disease and fear of disease progression affects psychosocial adjustment and quality of life. The purpose of this study was to validate a Norwegian short version of the “The Mishel Uncertainty in Illness Scale” (SF-MUIS) and to examine the impact of uncertainty in illness in breast cancer patients.

**Method and sample:** 209 patients in breast cancer treatment completed questionnaires for SF-MUIS, Hospital Anxiety and Depression Scale (HADS), the Functional Assessment of Cancer Therapy-Breast (FACT-ES), and eight questions concerning quality of the patient information provided (IQP). Relationship between scores on uncertainty in illness and anxiety, depression, social support, emotional well-being, the quality of patient information provided, and age were studied by multiple regression analyses. **Results:** Ordinal coefficient alpha for the Norwegian version of SF-MUIS was 0.70. Scores on SF-MUIS correlated significantly with scores on HADS ( $P = 0.001$ ), FACT-ES ( $P = 0.001$ ), and IQP ( $P = 0.001$ ) indicating good convergent validity. The patients reported a moderate degree of uncertainty in illness. However, those who had been diagnosed with breast cancer for a year, reported higher scores than those newly diagnosed ( $P = <0.0001$ ). Information provided was the sole significant predictor of illness uncertainty ( $P = <0.0001$ ).

**Conclusion:** The results of the present study confirm that the Norwegian version of the SF-MUIS is a suitable tool for assessment of uncertainty in breast cancer patients, who reported a moderate degree of uncertainty in illness.

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### Introduction

In Norway, breast cancer comprises more than 20% of all female cancers, with an incidence indicating that about one in 12 women develop the disease before the age of 75 (Hofvind et al., 2013; Larønningen et al., 2013). The 5 year survival rate of breast cancer is increasing. Reduced use of postmenopausal hormone

replacement therapy (HRT) and mammographic screening programs have been argued as the main reason as to why this is the case (Hofvind et al., 2013; Larønningen et al., 2013). At the end of year 2011, about 38500 women in Norway were either under active treatment or had been treated for breast cancer (Hofvind et al., 2013; Larønningen et al., 2013).

Living with the uncertainty of breast cancer during the diagnosis period and after completed treatment may present a life-long challenge because of the chronic nature of the disease (Mishel, 1999). Patients report exacerbation of symptoms and fear about disease progression before mammogram checkup, and studies show that symptom unpredictability and an unknown future have

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been identified as causes of uncertainty (Gill et al., 2004; Mast, 1998). Uncertainty is defined as “the inability to determine the meaning of illness-related events” (Mishel, 1981). The condition reflects neither a desired nor a dreaded state until the implications of the uncertainty are determined (Mishel, 1988). High uncertainty is associated with reduced ability to process new information, predict outcomes, and adapt to the cancer diagnosis (Mishel, 1990). Illness uncertainty and fear of disease progression affect psychosocial adjustment and quality of life (Knobf, 2007; Mast, 1995; Sammarco, 2003). A high degree of uncertainty is shown several years after treatment (Decker et al., 2007; Hall et al., 2014), and this may be one of the greatest challenges for breast cancer survivors (McCormick, 2002; Wonghongkul et al., 2000). Although factors that trigger uncertainty may change over time, distressing symptoms and fear of recurrence are strongly associated with increased illness uncertainty and emotional distress (Decker et al., 2007; Hall et al., 2014).

Information from health workers on cause, intensity, and duration of symptoms have been reported to be a major factor in reducing illness uncertainty (Mishel, 1997).

The original Mishel Uncertainty in Illness Scale (MUIS or MUIS-A) from 1981 consisted of 33 statements and examined uncertainty in hospitalized adult patients (Mishel, 1981). The scale was later modified to evaluate the perception of uncertainty in illness related to four factors; ambiguity, complexity, unpredictability, and inconsistent information through the entire disease trajectory (Mishel, 1990). Furthermore, the modified scale measured unremitting uncertainty about life changes in cancer patients during the diagnostic period, treatment phases, and in long term cancer survivors (Mishel, 1990). In addition, several other versions of the MUIS have been developed for different contexts (Mishel, 1983). For non-hospitalized adults, a 23 item community version has been established (MUIS-C) (Mishel, 1997), and there is a scale that measures the experience of uncertainty among parents with a sick child, the 31 item Parents' Perception of Uncertainty in Illness Scale (PSSU) (Stewart et al., 2010). Furthermore, there are studies using 23 and 17 questions of the original MUIS (Liao et al., 2008; Wonghongkul et al., 2000).

In 2013, a 5 item short form of MUIS was available from The University of North Carolina at Chapel Hill web site

([https://nursing.unc.edu/files/2012/12/mishel\\_uncertainty\\_scales.pdf](https://nursing.unc.edu/files/2012/12/mishel_uncertainty_scales.pdf)).

The 5 items represent the factors ambiguity; concerning the state of the illness, and complexity; regarding treatment and system of care, the controllability of the illness. When the 5 item scale was established, we can only assume that the factors ambiguity and complexity were chosen in the 5 item short form of MUIS because they have demonstrated a more consistent reliability (Neville, 1998), and are shown to be important in cancer patients (Mishel, 1983). As far as we know, the short form of MUIS was established in 2012, but never used in any study.

Despite the importance of the concept of uncertainty in illness in cancer patients, no reliable and valid tool exists in Norwegian. Using the original MUIS cross-culturally may affect the validity of the scale, which has shown to be the case in Asian and Nordic studies (Hallberg and Erlandsson, 1991; Mishel, 1991). Also, the type of alpha coefficient used in the reliability test in these versions of the scale may affect the validation. In scales with ordinal Likert-type responses, the ordinal alpha has shown to estimate reliability more accurately than the Cronbach's alpha, especially in the short form scales (Gadermann et al., 2012).

An applicable short form of the MUIS might be easier and more suitable to use than the long version of the scale, when it comes to identifying patients which need additional health support. Therefore, the purpose of this study was to translate and test the

psychometrics of a Norwegian short form of the MUIS (SF-MUIS), and examine the uncertainty in illness in breast cancer women.

## Methods

### Patients and settings

Between January 2012 and June 2013, 281 consecutive patients above 18 years of age diagnosed with breast cancer, at two university hospitals, were eligible for inclusion in the study. All the patients had to be in curative treatment for breast cancer (surgery, chemotherapy, radiation, and endocrine treatment), and able to speak, read and write Norwegian. Pre-operatively the patients were telephoned, informed about the study, and asked to participate. Basically all agreed to participate and were mailed a letter explaining the study, four questionnaires, a consent form and a stamped envelope for return mail. In addition, demographic information included age, gender, marital status, and years of education. 229 patients (81.5%) returned the completed questionnaires, 52 patients did not answer after one reminder. Also, 20 patients dropped out due to different reasons (Fig. 1). Thus the remaining 209 patients (74%) were included in the study. Because of the study design, one group filled in the questionnaires 0–4 weeks ( $N = 65$ ), a second 4–24 weeks ( $N = 65$ ), and a third 24–52 weeks ( $N = 79$ ) after their breast surgery, denominated subgroups A, B, and C respectively. The first 30 patients, who returned the SF-MUIS, were asked to complete it once more four weeks later. All the patients gave written informed consent, and the Regional Committee for Medical Research Ethics (REK–Nord nr. 2011/2161) and The Norwegian Social Science Data Services approved the study.

### Instruments

#### Short – form Mishel Uncertainty in Illness Scale (SF-MUIS)

The SF-MUIS covers five statements from the modified 33 questions MUIS (Mishel, 1990), examining the uncertainty in illness in hospitalized adults asking the participants to reflect and report how they agreed to the following 5 statements; “I have a lot of questions without answers”, “I understand everything explained to me”, “The doctors say things to me that can have many meanings”, “There are so many different types of staff; it's unclear who is responsible for what”, and “The purpose of each treatment is clear

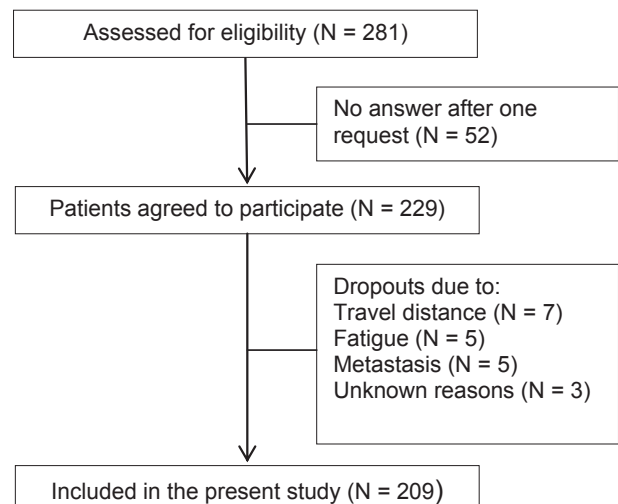


Fig. 1. Flowchart of the participants ( $N = 209$ ).

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