Patient Education and Counseling 97 (2014) 200–210

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

Medical decision making

# Adapting the coping in deliberation (CODE) framework: A multi-method approach in the context of familial ovarian cancer risk management

Jana Witt [a,*], Glyn Elwyn [b,c], Fiona Wood [d], Mark T. Rogers [e], Usha Menon [f], Kate Brain [d]

[a] Department of Palliative Care, Policy and Rehabilitation, King's College London, London, UK
[b] Dartmouth Center for Healthcare Delivery Science, Hanover, NH, USA
[c] Dartmouth Institute for Health Policy and Clinical Practice, Hanover, NH, USA
[d] Cochrane Institute of Primary Care and Public Health, Cardiff University, Cardiff, UK
[e] All Wales Medical Genetics Service, Cardiff, UK
[f] Women's Cancer, Institute for Women's Health, University College London, London, UK

ARTICLE INFO

*Article history:*
Received 12 June 2013
Received in revised form 28 June 2014
Accepted 3 July 2014

*Keywords:*
Deliberation
Coping
Qualitative
Oophorectomy
Ovarian cancer

ABSTRACT

*Objective:* To test whether the coping in deliberation (CODE) framework can be adapted to a specific preference-sensitive medical decision: risk-reducing bilateral salpingo-oophorectomy (RRSO) in women at increased risk of ovarian cancer.
*Methods:* We performed a systematic literature search to identify issues important to women during deliberations about RRSO. Three focus groups with patients (most were pre-menopausal and untested for genetic mutations) and 11 interviews with health professionals were conducted to determine which issues mattered in the UK context. Data were used to adapt the generic CODE framework.
*Results:* The literature search yielded 49 relevant studies, which highlighted various issues and coping options important during deliberations, including mutation status, risks of surgery, family obligations, physician recommendation, peer support and reliable information sources. Consultations with UK stakeholders confirmed most of these factors as pertinent influences on deliberations. Questions in the generic framework were adapted to reflect the issues and coping options identified.
*Conclusions:* The generic CODE framework was readily adapted to a specific preference-sensitive medical decision, showing that deliberations and coping are linked during deliberations about RRSO.
Practice Implications: Adapted versions of the CODE framework may be used to develop tailored decision support methods and materials in order to improve patient-centred care.


## 1. Introduction

Previous research suggests that emotions influence appraisal of future events, that emotions and coping are integral parts of decision processes and that medical decisions are in fact coping behaviours aimed at regulating a health threat and associated emotions [1–4]. To date, however, decision-making theorists have paid little attention to emotions and coping in healthcare decision-making.

We recently proposed a novel framework that describes deliberations in the context of preference-sensitive healthcare choices as a multi-step coping process [5]. The coping in deliberation (CODE) framework acknowledges the role of emotions and coping mechanisms, in addition to cognitive processes, during decision-making. It describes specific events associated with the process of decision-making as 'deliberation phases'. These phases include disclosure of the diagnosis/health threat, discussion of choice, presentation of options and preference construction (Fig. 1). The CODE framework proposes that each deliberation phase gives rise to a primary and secondary appraisal process and coping response [5]. Primary appraisal describes the process of cognitively and emotionally appraising an event's meaning, relevance and level of threat [6]. According to Leventhal's [7] self-regulatory model, cognitive appraisal explores the identity of the threat, its causes, timeline, consequences and opportunities for control [8,9]. Emotional appraisal is guided by emotions induced by the threat and can influence cognitive appraisal

* Corresponding author at: Palliative Care, Policy and Rehabilitation, Cicely Saunders Institute, 2nd Floor, 6 Bessemer Road, Denmark Hill, London SE5 9PJ, UK. Tel.: +44 02078480753.
*E-mail addresses:* jana.witt@kcl.ac.uk, witt.jana@gmail.com (J. Witt).

http://dx.doi.org/10.1016/j.pec.2014.07.004
0738-3991/

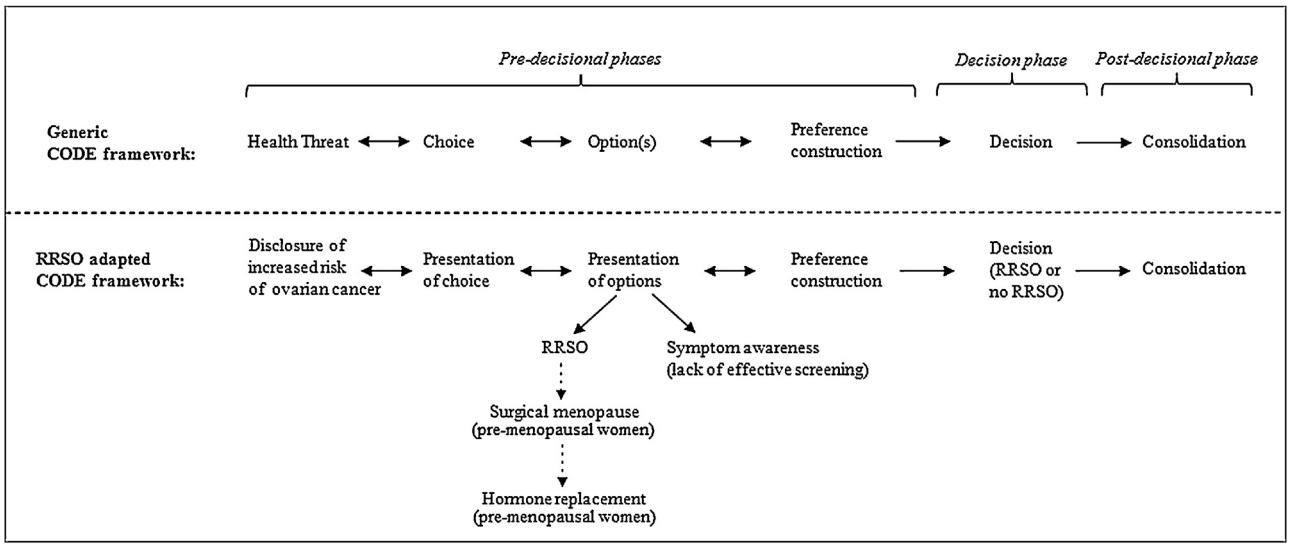


**Fig. 1.** Deliberation phases in the generic and RRSO-adapted CODE framework.

processes [2,10]. Secondary appraisal describes appraisal of the coping potential (i.e. whether anything can be done) and options (i.e. what can be done) to manage stressful events [6,11]. Potential coping options that might be implemented in response to a threat may be defined as problem- or emotion-focused [6].

The CODE framework outlines questions patients might ask and coping options patients might explore when making tough choices about their health. The generic CODE framework currently represents a theoretical description of deliberation and coping processes, and requires adaptation to determine whether it can be used as a model of specific preference-sensitive decisions. Hence, the aim of this study was to test whether the generic CODE framework can be adapted to describe the deliberation and coping process associated with a selected preference-sensitive decision. To the authors' knowledge this is the first study to report a systematic adaptation of the generic CODE framework.

## 2. Methods

This study used a multi-method approach, including a systematic literature search, focus groups and interviews. The study received approval from the Multi-Centre Ethics Committee for Wales.

### 2.1. Decision selection

The rationale behind selecting the decision about risk-reducing bilateral salpingo-oophorectomy (RRSO) faced by women at increased risk of ovarian cancer was twofold. First, ovarian cancer poses a considerable burden due to the lack of effective screening, late diagnosis and poor outcomes [12–15]. This especially affects those at the highest risk, of whom up to two in five may develop ovarian cancer [16,17]. Second, previous research has shown the inherent complexity of decisions regarding RRSO, including the role of emotions, past experiences, personal preferences and the variety of coping responses [18–27]. These factors make this decision an ideal candidate for depiction in the CODE framework.

### 2.2. Literature search

A systematic search of the literature was conducted to identify the range of factors, questions, concerns, needs and coping strategies that may play a role in women's appraisals of and deliberations about RRSO. The search focused on literature published between 1996 and July 2012. Databases included Embase, MEDLINE and PsycINFO. Search terms for the title search included 'Decision', 'Choice', 'Option' and 'Perception' as well as 'Risk-reducing (salpingo) oophorectomy', 'Familial ovarian cancer' and 'BRCA'. Only original research articles were included. Publications were excluded if they were not concerned with decision-making processes, cancer risk reduction/prevention, ovarian cancer and/or oophorectomy, if they exclusively included participants not at increased risk of ovarian/breast cancer or if they did not explore women's characteristics, self-reported intentions, opinions or concerns. Additional relevant publications were identified through previously published reviews by Fang et al. [18], Howard et al. [20], de Leeuw et al. [28] and Miller et al. [29]. Issues important during decision-making about RRSO were extracted from studies, categorised into medical, psychological, social or demographic themes, and later compared to data from stakeholder consultations, i.e. focus groups with women at increased risk and interviews with health professionals.

### 2.3. Focus groups with patients

Focus groups with women at increased risk of ovarian cancer who were currently making decisions about RRSO were conducted to further explore women's deliberations and identify specific questions, concerns and support needs to complement data from the literature. Patients were identified from databases of three genetics centres in Wales and England (University Hospital of Wales (Cardiff), Singleton Hospital (Swansea) and University College London Hospital (London)) and were then invited to the study by health professionals. Women were eligible if they had an estimated lifetime risk of ovarian cancer $\geq$10%, were aged 30–80 and had not yet made a decision about RRSO. All eligible women registered with the three centres at the time were invited. Focus groups were moderated by JW and participants were asked to discuss questions/concerns important during decision-making about RRSO, to consider catalysts and barriers to decision-making, and to explore their decision support needs.

### 2.4. Interviews with health professionals

Additionally, semi-structured interviews were conducted with health professionals involved in the care of patients at increased risk of ovarian cancer. A purposive sample of eligible professionals,