



A content analysis of emotional concerns expressed at the time of receiving a cancer diagnosis: An observational study of consultations with adolescent and young adult patients and their family members



Live Korsvold ^{a, b, *}, Anneli Viktoria Mellblom ^a, Arnstein Finset ^a, Ellen Ruud ^b,
Hanne Cathrine Lie ^{a, b, c}

^a Department of Behavioural Sciences in Medicine, Institute of Basic Medical Sciences, Faculty of Medicine, University of Oslo, Norway

^b Department of Paediatric Medicine, Children's and Adolescents Division, Oslo University Hospital, Norway

^c National Resource Centre for Late Effects after Cancer Treatment, Oslo University Hospital, Radiumhospitalet, Norway

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ABSTRACT

Purpose: Little is known about the emotional concerns expressed by adolescent and young adult (AYA) patients in consultations when a diagnosis of cancer is delivered. Here, we investigated the content of such concerns and how health care providers respond to them.

Method: We audio-recorded nine consultations with AYA cancer patients (ages: 12–25 years) at the time of diagnosis. We have previously identified and coded 135 emotional concerns and the responses to these in the nine consultations using the Verona Coding Definitions of Emotional Sequences (VR-CoDES) framework. Here, we used qualitative content analysis to study these emotional concerns and categorize them according to overarching themes. We then quantitatively explored associations between the themes of the concerns and whether the responses to them varied according to their themes.

Results: We identified four themes for the content of concerns: “Side-effects/late-effects” (39%), “What happens in the near future/practical aspects” (16%), “Fear” (27%) and “Sadness” (17%) (e. g. crying, sighing or other sounds that expressed sadness). Health care providers' responses did not appear to vary according to the different themes of concerns, but typically consisted of providing medical information.

Conclusion: The content analysis revealed that patients and family members expressed a wide range of emotional concerns. Health care providers tended to respond to the content-aspect of the concerns, but did rarely explicitly acknowledge the affective-aspect of the concerns. The effect of responses to patients' emotional concerns in the important first consultations about the cancer diagnosis and planned treatment should be investigated in future studies.

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1. Background

Receiving a cancer diagnosis and a treatment proposal may cause a range of emotional concerns in adolescent and young adult (AYA) patients and their family members. In the first consultations after the diagnosis is confirmed, patients typically receive information about their cancer diagnosis and the treatment. The treatment is often tough and long-lasting with considerable side effects,

resulting in an upheaval of everyday life for the patient and his or her family. Given their young age, AYA cancer survivors have reported not being prepared for receiving a potentially deadly disease like cancer (Miedema et al., 2007; Zebrack et al., 2014a). Moreover, they report higher levels of psychosocial distress and anxiety at diagnosis than older patients (Lang et al., 2015). Although the initial phase of the cancer trajectory is an emotionally intense and tumultuous time for all involved, this is, to the best of our knowledge, the first study to explore the content of emotional concerns expressed by AYA patients and their family members at this time and how health care providers (HCPs) respond according to the content of these.

Knowledge of the content of emotional concerns, i.e. what substantive issues that patients are concerned about and how these

* Corresponding author. Department of Behavioral Sciences in Medicine, Institute of Basic Medical Sciences, PO Box 1111, Blindern, 0317 Oslo, Norway.

E-mail addresses: live.korsvold@medisin.uio.no (L. Korsvold), anneli.mellblom@medisin.uio.no (A.V. Mellblom), arnstein.finset@medisin.uio.no (A. Finset), elruud@ous-hf.no (E. Ruud), h.c.lie@medisin.uio.no (H.C. Lie).

issues and concerns are responded to by HCPs may be important for several reasons. First, there is evidence that the strength and the nature of the psychological reactions of adult patients receiving a cancer diagnosis are influenced by the communication strategies of the HCPs, including responses to patients' emotional concerns (Schofield et al., 2003). Second, the ways in which patients' and family members' emotional concerns are handled by HCPs may have an effect on the immediate and long-term wellbeing of patients and their family members (e.g., by reducing anxiety and promoting positive emotions during times of distress) (Street et al., 2009) and more indirectly affect health outcome (Street, 2013; Street et al., 2014). Third, both adult and AYA patients and their family members expect high-quality information about the disease and the treatment, but they also want this information to be provided in a sensitive and empathic way (Finset et al., 1997; Young et al., 2013; Zebrack et al., 2007). Fourth, even though AYA oncology has emerged as its own field over the last decade, there is still need for more knowledge about the characteristics of this patient group and how to communicate with them (Thomas et al., 2010; Zebrack et al., 2014b).

Physicians, both in adult care and in pediatrics, have reported that they find communicating with AYAs challenging (Drury, 2003; Levetown, 2008; Sawyer et al., 2007; Stenmarker et al., 2010) and delivering bad news to adolescents to be especially challenging (Stenmarker et al., 2010). In addition, HCPs often fail to assess the communication preferences of individual AYA patients (Sawyer et al., 2007), and tend to underestimate psychosocial distress and the need for psychosocial support in AYA cancer patients (Hedstrom et al., 2006; Keegan et al., 2012; Thompson et al., 2013). Communicating with AYA patients may be challenging for the HCP for several reasons. HCPs, patients and their family members often do not know each other well at the time of diagnosis (Fallowfield and Jenkins, 2004). Moreover, adolescence and young adulthood coincide with a period of great physical, psychological and social changes. AYAs typically experience and express stronger emotions (Arnett, 2014). Between the ages of 12 and 25, the human brain is in the midst of physiological development and hormonal changes that contribute to decreased goal-oriented behaviors, organization, planning and impulse control compared with adults (Casey et al., 2008; Giedd, 2008; Steinberg, 2011). At the same time, AYAs seek independence from their parents, and peer relations and intimate relationships become increasingly important (Arnett, 2014). However, AYAs with cancer often become more dependent on their parents than before their cancer diagnosis, and appreciate their parents' help with the communication with physicians at the time of diagnosis (Olsson et al., 2016, in preparation). In sum, HCP-patient communication during the emotionally intense, initial consultations of cancer care can have implications for further adjustment and satisfaction with the care provided.

There are no guidelines specially designed for the delivery of bad news to AYAs in oncology, but general guidelines highlight the patients' needs for information and for the importance of expressions of empathy by HCPs (Baile et al., 2000). Although AYA patients with cancer tend to be satisfied with their medical care, receiving insufficient information about the diagnosis and a perceived lack of empathy by the HCPs have been associated with dissatisfaction (Zebrack et al., 2014a, 2014b). Being sensitive and responding to emotional concerns expressed by the patient or their family may be a way for HCPs to show empathy when delivering bad news.

We lack knowledge of the content of AYAs' concerns and how they are responded to during the initial HCP-patient encounters. In a previous observational study from the same sample as the present one (Korsvold et al., 2016) we investigated the expression of emotional utterances and HCP responses from an interaction analysis point of view during real-life consultations in which AYAs

were informed about their cancer diagnosis using the Verona Coding Definitions of Emotional Sequences (VR-CoDES) system (Del Piccolo et al., 2011; Zimmermann et al., 2011). However, in that paper we did not report the content of the concerns, that is the actual issues the patients and parents expressed concerns about. The aim of the current study is therefore to *explore the previously identified emotional concerns further* by investigating (a) the content of the emotional concerns expressed by AYA patients and their family members and (b) associations between the content of the emotional concerns and potential patterns of HCPs response to these concerns.

2. Methods

2.1. Design

We extracted data from our explorative, mixed-methods study (qualitative and quantitative methods) of audio-recorded consultations in which patients were informed about their cancer diagnosis and presented with a proposal for a treatment plan.

2.2. Ethics

The Regional Committee for Medical and Health Research Ethics approved the study (reference number 2011/2290). Only the members of the research group listened to the tapes to ensure the confidentiality of the participants.

2.3. Sample and setting

AYA patients aged between 12 and 25 years were included because this age range coincides with the start and end of pubertal neurocognitive development (Steinberg, 2011). We recruited patients from two adult medical wards and one pediatric ward at Oslo University Hospital (Norway). The AYA patients were about to attend a consultation where they would receive a cancer diagnosis and a treatment proposal that included chemotherapy. The consultations under study were identified by the attending HCPs to be "the information consultation" which is the first consultation after the diagnosis has been ascertained. In this consultation they would provide information about the diagnosis and the proposed treatment. We do not know what the patients already knew about their diagnosis and possible treatment. It is likely that most of the patients were aware of the impending cancer diagnosis because they had been through various medical tests and examinations leading up to the "information consultation". Participants were required to have sufficient Norwegian fluency (no interpreter needed) and be able to provide informed consent.

We included patients consecutively. Of the eleven invited patients, one patient declined to participate and one patient terminated the audio-recordings and withdrew her consent. Because of logistical or recruitment problems due to the short timeframe between the patients' arrival at the hospital and the consultation a number of eligible patients were not included in the study. Many patients had their treatment at other wards than where the consultations were carried out. The exact number of "lost" patients therefore unfortunately is unknown. In addition, there are few patients in the chosen age group both in adult and pediatric wards and the project seemed to be forgotten despite frequent reminders. Patients were included between September 2012 and January 2014. We ended the data collection when we considered the information power of the data to be sufficient for the planned analysis (Malterud et al., 2015); see Table 1.

The patient, at least one close family member, a physician and a nurse attended the consultations, as is normal procedure in Norway

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