

UNDERSTANDING OF CANCER TERMINOLOGY AMONG UZBEK PEOPLE

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Annotation. *The objective of this study was to replicate and extend an earlier studies examining lay people's understanding of cancer-related terms in a Uzbek sample by examining understanding of general terms relating to diagnosis, prognosis, treatment and an experimental study of the effects of medical jargon versus plain language on people's perceptions of the effectiveness of interactions with oncologists, participation in medical decision making and interpersonal trust.*

Key words: *Uzbek people, cancer terminology, medical jargon, common terms, translation problems.*

Аннотация. *Целью данного исследования было повторить и расширить более ранние исследования, посвященные изучению понимания неспециалистами терминов, связанных с раком, в узбекской выборке путем изучения понимания общих терминов, касающихся диагностики, прогноза, лечения, а также экспериментального исследования влияния медицинского жаргона по сравнению с простым языком о восприятии людьми эффективности взаимодействия с онкологами, участия в принятии медицинских решений и межличностного доверия.*

Annotatsiya. *Ushbu tadqiqotning maqsadi tashxislash, bashorat qilish va davolash bilan bog'liq umumiy atamalarni tushunish va tibbiy jargon ta'sirini eksperimental o'rganish orqali o'zbek tili lug'atidagi odamlarning saraton bilan bog'liq atamalarni tushunishini o'rganuvchi oldingi tadqiqotlarni takrorlash va kengaytirish. Odamlarning onkolog shifokorlar bilan o'zaro munosabatlarning samaradorligi, tibbiy qarorlar qabul qilishda ishtirok etishi va shaxslararo ishonch haqidagi tasavvurlarini kengaytirishida umumiy til shakllanishidagi rolini oshirishga qaratiladi.*

Cancer patients often misunderstand their diagnosis, prognosis, or treatment options. This lack of understanding may be due to the complexity of information and the emotional nature of cancer consultations. However, it can also be a result of the language doctors use, including euphemisms, vague words, and medical jargon. Chapman examined lay people's understanding of cancer-related terms that oncologists use when discussing cancer diagnosis and prognosis with their patients and found that understanding was suboptimal and inconsistent.



Limited patient understanding can hinder effective physician-patient communication in a variety of ways. First, the use of jargon, such as technical terms or ambiguous language, can reduce the effectiveness of patients actively interacting with their oncologist and participating in decision-making. For example, patients' overall understanding of health information, that is, their health literacy, has been shown to be positively associated with patient engagement during consultation. Limited participation in consultation and decision-making has been reported to be associated with negative consequences, such as receiving less information and lower quality of life.

Moreover, it was shown that patients with low levels of perceived self-efficacy were less satisfied with the consultation. Second, the use of unclear and incomplete information may reduce patients' trust in their oncologist. A recent review found that low levels of trust complicate communication and decision-making and negatively impact patient outcomes such as psychological well-being.

The present study primarily aims to replicate and extend the descriptive study of Chapman in a large sample in the UK, examining lay people's understanding of terms related to diagnosis, treatment and prognosis, and statistics. Second, we sought to experimentally examine the impact of language use (jargon versus plain) on laypersons' perceptions of the effectiveness of interactions with an oncologist, participation in medical decision making, and trust. Third, we sought to examine whether the possible effect of language on outcomes would be moderated by people's confidence in understanding cancer-related terms.

One hundred and eighty lay participants completed a questionnaire assessing comprehension, confidence in understanding, and anxiety after reading 20 scenarios representing cancer-related terms and perceived communication effectiveness, decision-making effectiveness, and trust in a brief case study depicting an oncologist using jargon or simple language.

Individuals meeting the criteria were invited to participate and were informed of the purpose and procedure of the study. After verbal consent was obtained, participants were seated and asked to complete the questionnaire. The researcher alternated slang and simple versions of the questionnaire. Care was taken to ensure that participants did not search for information when completing the questionnaire. The institutional ethics board approved the study.

Participants were asked to indicate whether they believed that their knowledge about cancer was above average due to having experience with cancer in their personal life (yes/no) or through education or work (yes/no)). In addition, participants reported their age, gender and level of education. Educational level was classified as low (primary/low vocational; <9 years of schooling education), secondary (average level of professional education; 10–14 years), high (highest level of professional/academic level; >15 years).

The questionnaire asked participants to imagine that they were a cancer patient. To assess comprehension, 20 short scenarios were presented in which

the oncologist used technical or potentially ambiguous language, that is, euphemisms, modifiers, or prognostic, diagnostic, or probabilistic terms related to diagnosis, prognosis, or treatment. Five scenarios were obtained from Chapman, two from Sutherland, and three were based on a purposive sampling of videos of Dutch radiation oncologists' first consultations with patients with different types and stages of cancer. These consultations were recorded as part of an unrelated observational study and served as inspiration for the development of three additional scenarios corresponding to Uzbek practice. The resulting scenarios were checked for veracity by two surgeons and one radiation oncologist. Participants were asked to indicate what they thought the oncologist was saying using an open-ended response format (three scenarios) or a multiple-choice response format (seven scenarios). To replicate Chapman's study as closely as possible, we adopted the response formats they used for the questions generated from their study. Closed scenarios other than Sutherland et al. "Don't know" response option included. Participants were also asked to indicate for each scenario how confident they were in their understanding (1 = not at all confident, 2 = not confident, 3 = somewhat confident; 4 = confident and 5 = very confident) and how worried they were. They viewed the scenario (1 = not at all annoying, 2 = not at all annoying, 3 = slightly annoying, 4 = annoying, and 5 = very annoying) as additional indicators of understanding.

Experimental manipulations

To experimentally examine the effects of language, participants were presented with one of two vignettes. Again, these were developed using content and terminology taken from the example videos first consultations with radiation oncologists. In the episodes, the oncologist provided information about treatment options in jargon or plain language. As a manipulation check, participants were asked to indicate whether they found the wording used difficult (1 = strongly disagree, 2 = disagree; 3 = neither disagree nor agree; 4 = agree; 5 = strongly agree).

Criteria for evaluation

Participants' perceived effectiveness of interactions with their oncologist was measured using the five-item Perceived Effectiveness of Patient-Provider Interaction Scale. Participants were asked to indicate how confident they were that, for example, they would be able to get their questions answered by the physician presented or that they would be able to get the most out of their visit. Internal consistency was high. Higher total scores (range 5–25) indicate higher perceived effectiveness. Participants' perceived decision-making participation self-efficacy was assessed using the five-item Decision-Making Participation Self-Efficacy Scale. The DEPS assesses patients' confidence in participating in decision making, such as confidence that they can tell their doctor which treatment option they prefer. Internal consistency was high. Higher total scores (range 5–25) indicate higher perceived self-efficacy. Participants' trust in their oncologist was assessed using two items from the Wake Forest Physician Trust Scale: "You are



not worried about putting your life in the hands of this doctor” and “You trust this doctor completely.” Internal consistency was high. Higher total scores (range 2–10) indicate higher overall trust.

Two hundred people agreed to take part. Data were available from 180 participants (two did not return the questionnaire; four answered less than half of the questions). The various scales were completely completed by at least 95% of the participants. The average age was $38. \pm 13.1$ years, 60.5% were men. The majority (76.2%) had higher education, 15.1% had secondary education, and 4.2% had secondary education. One third (36.5%) indicated that they may have more knowledge about cancer than average because they have had experiences with cancer in their personal life (31.9%) or at school/work (13.2%). Participants in the two conditions did not differ significantly on any background characteristics.

To our knowledge, this study is the first in the Uzbekistan to examine lay people’s understanding of common cancer-related terms. The results indicate that participants’ understanding was suboptimal, that is, the scenarios were misunderstood by a significant number of people, and the number of correctly understood scenarios varied greatly between them. It can be argued that the laity the understanding does not have to be perfect because they do not personally suffer from cancer. However, most scenarios relate to situations that may arise during or shortly after diagnostic consultations, such as “sprouts”, “spots”, “positive” or “benign”. Level of their understanding, especially in the early post-diagnostic period.

In conclusion, these and other findings suggest that laypersons’ understanding of commonly used terms in cancer consultations is suboptimal. This study also shows that people’s confidence in the oncologist’s understanding was associated with their perceptions of the effectiveness of participating in the consultation. Clinicians should be aware that especially patients with newly diagnosed cancer may have difficulty understanding their situation and options, which may result in patients being less involved in their care than they would like. Such participation is important because it can help clinicians tailor information as well as decision making to the needs of the individual patient. Adaptation and sharing solutions with patients has been shown to be associated with

favorable patient outcomes such as quality of life and adjustment. To reduce unnecessary anxiety and promote active patient participation, clinicians should regularly assess patients’ understanding during consultations.

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