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Health literacy, information provision and satisfaction in advanced cancer consultations: two observational studies using level of education as a proxy

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Abstract

Objectives Patients with low health literacy (LHL) might feel less informed and satisfied with provided information than patients with high health literacy (HHL). In the setting of advanced cancer, we explored whether LHL patients, compared with HHL patients are: (1) often less informed, and (2) less satisfied with clinicians' communication (a) in general and (b) following information provision specifically.

Methods Data from two observational studies using recorded consultations were combined. Clinicians' provided information and patients' health literacy level—defined by educational levels—and satisfaction were measured. X² tests and regression (moderation) analyses assessed the relation between health literacy and information provision, and between information provision and satisfaction, meanwhile exploring moderating influences of health literacy.

Results Of 61 included patients, 25 (41%) had LHL. LHL and HHL patients were equally seldom informed about the disease's incurability (36% vs 42%, $p=0.66$). LHL patients were more often informed about the option of not pursuing anticancer therapy than HHL patients (28% vs 8%, $p=0.04$). LHL patients were more satisfied with clinicians' communication than HHL patients ($M=9.3$ vs $M=8.5$, $p=0.03$), especially when the option

of no anticancer treatment was discussed ($p=0.04$). Discussing the disease's incurability did not influence satisfaction levels ($p=0.58$) for LHL and HHL patients.

Conclusions LHL patients were not less informed, yet more satisfied than HHL patients. Both groups were equally seldom informed about the disease's incurability. No anticancer therapy was mostly discussed with LHL patients who were more satisfied following this information. Clinicians should be encouraged to inform all patients about the disease status and (non)treatment options, while not overlooking empathic support.

Key messages

What was already known?

- Information provision is a prerequisite for patient-centred care in serious illnesses such as advanced cancer.
- Patients with low health literacy (LHL) might feel less informed and satisfied with provided information than patients with high health literacy (HHL).

What are the new findings?

- LHL patients are not less informed, yet more satisfied than HHL patients.
- Both groups are equally seldom informed about the disease's incurability. No anticancer therapy is mostly discussed with LHL patients who are more satisfied following this information.

What is their significance?

- a. Clinical: Clinicians should be encouraged to inform all patients about the disease status and (non)treatment options, while not overlooking empathic support.
- b. Research: Larger studies should assess health literacy with appropriate tools and use longitudinal designs linking communication with patient needs and outcomes

Background

Information provision is a prerequisite for patient-centred care in serious illnesses such as advanced cancer. Patients with low health literacy (LHL) might feel less informed than their high health literate (HHL) counterparts.^{1,2} It is unknown whether LHL patients are also *objectively* less informed than HHL patients in the setting of advanced cancer

Moreover, health literacy might be negatively related to satisfaction with provided information. In a study among patients with early and late stage ovarian cancer, 33% of LHL patients felt satisfied with the information they had received compared with 63% of HHL patients.² It is unknown whether, in advanced cancer solely, LHL patients are less satisfied with provided communication and information than HHL patients.

The aim of the current study conducted among patients with advanced cancer is twofold. First, to determine whether LHL patients (defined by low educational levels) are less often informed (about the incurability of their illness and about the option of not pursuing anticancer therapy, called 'no anticancer treatment') than HHL patients. Second, to determine whether LHL patients are less satisfied than HHL patients with clinicians' communication (a) in general and (b) after information provision (about the disease's incurability and the option of no anticancer treatment) specifically.

Methods

Design, participants and recruitment

We used data (collected in 2018) from two observational studies in advanced cancer care. Procedures have been described (eg, ^{3,4}).

For study 1, we included female patients >18 years of age with incurable breast cancer scheduled for a test-result/incurable cancer diagnosis consultation, with sufficient command of Dutch language. For study 2, we included patients >18 years of age with incurable cancer, with sufficient command of Dutch language and LHL; based on (pre)primary/lower secondary education and/or screening questions or clinicians' views.

For study 1, patients were approached by the hospital via phone, and when interested by the research team. Information was sent via post. Written informed consent was obtained preceding the consultation. For study 2, patients were approached by the hospital/research team by phone, and when interested met by the research team preceding the consultation when written consent was obtained.

Procedure and outcomes

The consultations were recorded (study 1: audiorecorded, study 2: video-recorded). Patients' characteristics (age, sex, educational level) and satisfaction with clinician's communication (1–10 scale ('not satisfied at all'–'extremely satisfied')) were assessed. For study 1, patients self-completed a (post-consultation) questionnaire. For study 2, characteristics (pre-consultation) and satisfaction (post-consultation) were assessed in a face-to-face interview.

Health literacy

Education was used as proxy for health literacy.⁵ Patients with (pre)primary and lower secondary education were grouped as 'LHL'; patients with upper secondary and tertiary education were grouped as 'HHL'. Although LHL can affect patients of all educational levels, 94% of (pre)primary, 77% of lower secondary, 56% of upper secondary and 32% of tertiary educated patients have inadequate health literacy.⁶

Analyses

First, background characteristics were described.

Second, transcribed consultations (for study 2: relevant parts) were reanalysed and scored on whether: (1) the disease's incurable nature was discussed (yes/no) and (2) the option of no anticancer treatment was discussed (yes/no). We assessed in how many consultations LHL versus HHL patients were informed about the disease's incurability and about the option of no anticancer treatment, and used χ^2 tests to determine whether these numbers differed significantly between the two groups.

Third, regression analyses assessed the relationship between health literacy and patient satisfaction. To assess whether the relationship between information provision (about the disease's incurability and the option of no anticancer treatment) and satisfaction is influenced by health literacy, first, a regression analysis assessing the relation between information provision and satisfaction was conducted. Second, interaction effects between health literacy (low/high) and information provision (yes/no) were created and additional regression analyses were run. Stata V.15 was used for all analyses.

Results

Participants

Complete data were available for 61 (out of 66; 41 from study 1 and 20 from study 2) participants; 25 (41%) had LHL and 36 (59%) HHL. Patients were relatively young (mean=61, SD=12.87) and predominantly female (N=52).

Association of health literacy and information provision

The disease's incurability was discussed in 39% (24 of 61) of the consultations; in 36% (9 of 25) of consultations with LHL patients and in 42% (15 of 36) of consultations with HHL patients. This difference was insignificant ($X^2=0.20$; $p=0.66$) (figure 1).

The option of no anticancer treatment was mentioned in 16% (10 of 61) of consultations; in 28% (7 of 25) of consultations with LHL patients and in 8% (3 of 36) of consultations with HHL patients. This difference was significant ($X^2=4.16$; $p=0.04$) (figure 1).

[Figure 1]

Association of health literacy, satisfaction and information provision

LHL patients were more satisfied with clinicians' communication than HHL patients (mean=9.27, SD=1.03 vs mean=8.53, SD=1.13; $p=0.03$, regression coefficient=-0.74, 95% CI=-1.41 to -0.07).

Patients' satisfaction did not depend on whether the disease's incurability was discussed ($p=0.13$, regression coefficient=-0.53, 95% CI=-1.22 to 0.16). Health literacy did not moderate this relationship ($p=0.29$, regression coefficient=-0.59, 95% CI=-1.70 to 0.52).

Patients' satisfaction did not depend on whether the option of no anticancer therapy was discussed ($p=0.58$, regression coefficient=-0.29, 95% CI=-1.32 to 0.75). Health literacy did moderate this relationship ($p=0.04$, regression coefficient=-2.2, 95% CI=-4.27 to -0.13); HHL patients were less satisfied after consultations in which the option of no anticancer therapy was discussed than LHL patients.

Discussion

In this study, we found that LHL patients, defined by a low educational level, were not less informed, yet more satisfied than HHL patients. More specifically, we found that the option of no anticancer therapy was discussed in more consultations with LHL patients than in consultations with HHL patients. LHL patients were more satisfied with clinicians' communication in general, and after consultations in which no anticancer treatment was discussed specifically.

When interpreting our results, it is important to take into account that in the majority of consultations, both the disease's incurability and the option of no anticancer therapy were not discussed at all; in 61% and 84%, respectively. Although this information might have been discussed in earlier consultations, these findings are in line with previous observational data reporting a lack of open information provision.⁷

We did, however, find that the option of no anticancer therapy was almost solely discussed with LHL patients. Perhaps LHL patients ask less about further treatment options, while clinicians experience difficulties in discussing ending anticancer treatment with more intellectual patients.⁸ Of course, it should be noted that we did not assess definite treatment decisions made. When death is near, patients from, for example, lower socioeconomic⁹ backgrounds (associated with LHL¹⁰) are prone to receive more aggressive care. So, our findings might not be representative of care received at the very end of life.

Next, we also found that LHL patients compared with HHL patients were more satisfied with the information provided, especially following the discussion of no anticancer therapy. We could

speculate that as most patients had a pre-established relationship with their clinicians, halo effects and feelings of dependency might have occurred which could be more prominent for LHL than HHL patients. More research into this finding is, however, needed before firm conclusions can be drawn.

These results have practical implications. The findings that the incurability and option of no anticancer treatment were seldom discussed are potentially worrisome. They might contribute to patients having overly optimistic treatment expectations,¹¹ which might influence treatment decisions. We would encourage clinicians to—if appreciated by patients—discuss all treatment options, including ‘wait and see’ and a sole focus on symptom management, with all patient groups. When doing so, it remains important for LHL patients to use simple language and check patients’ understanding of the provided information by using teach-back.^{4 12}

Also important, when providing information, clinicians should do so empathically. Clinician-expressed empathy can work as a double-edged sword. It facilitates patients’ information recall¹³ and helps LHL patients specifically to understand information better.¹⁴ Moreover, it is capable of decreasing anxiety levels while increasing satisfaction.¹⁵ So its use should be advised for both HHL patients—who, in our study, were most dissatisfied when no anticancer therapy was discussed—and LHL patients—for whom affective communication by clinicians is often missing.⁴

This study has limitations; most notably the combination of two relatively small datasets (possibly increasing the chance of type 1 errors due to multiple testing), although carried out by the same department, time frame and outcome measures. Moreover, as health literacy was not measured in study 1 (study 2 included only LHL patients), we used education as proxy, deviating from cited studies that did assess health literacy as such. We encourage future larger studies to assess health literacy with appropriate tools; and to use longitudinal designs focusing on clinicians’ communication, patients’ needs and outcomes, and on treatment and care decisions eventually made.

To conclude, in our study, LHL patients were not less informed, yet more satisfied than HHL patients. Both groups were equally seldom informed about the disease’s incurability. The option of no anticancer therapy was mostly discussed with LHL patients who were also more satisfied following the consultation in which this information was discussed. These findings suggest that clinicians should be encouraged to discuss this information with all patients, while empathic support should not be overlooked.

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Figure

Figur 1 Graphic display of discussion of incurability of illness and option of no anticancer treatment for total sample and LHL and HHL subsamples. HHL, high health literacy; LHL, low health literacy.

