The characteristics and effectiveness of Question Prompt List interventions in oncology: a systematic review of the literature

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Abstract

Objective: Question Prompt Lists (QPLs) have been used extensively in the oncology setting to improve communication, psychological and/or cognitive outcomes. In this systematic review, the objectives were to (a) examine the methodological quality of QPL interventions, (b) review the effectiveness of QPL interventions on communication, psychological and/or cognitive outcomes of cancer patients, (c) gain more insight into the characteristics of QPL interventions (e.g., the number and content of questions, and the mode of delivery) and (d) explore whether the effectiveness of QPL interventions might be explained by their characteristics.

Method: A systematic literature search was conducted in PsycINFO, Medline, CINAHL and CENTRAL. Empirical studies that investigated the use and effectiveness of QPL interventions in an oncology setting were included. The methodological quality of the included studies was assessed using the Cochrane method.

Results: Sixteen articles met the inclusion criteria. Results indicated evidence for the effectiveness of QPL interventions in enhancing patient participation (i.e., question asking). Furthermore, there was evidence that QPL interventions can influence psychological outcomes (i.e., anxiety at follow-up) and cognitive outcomes (i.e., recall of information). The majority of QPL interventions were given to patients before their consultation in hardcopy. In most studies, QPLs were combined with other intervention components. It is suggested that characteristics of a QPL intervention (i.e., the number of questions on a QPL and provider training) can influence its effectiveness.

Conclusion: Question Prompt List interventions are effective in improving communication, psychological and cognitive outcomes of cancer patients.

Background

Active patient participation during an oncology consultation can lead to positive outcomes for cancer patients including greater patient satisfaction, better treatment adherence and better recall of information [1–9]. Despite these benefits, there are still many patients who do not participate or do not participate as much as they would like to during their oncology consultation [10–13]. Patients can experience different barriers to participate such as communication barriers (e.g., forgetting questions) or agenda-setting barriers (e.g., doubting whether it is legitimate to ask certain questions in a consultation) [14]. The provision of a Question Prompt List (QPL) before a consultation might help patients to overcome these communication barriers [2]. A QPL is an inexpensive communication tool consisting of a structured list of questions designed to encourage information gathering. Patients can use these questions as examples which they can choose to discuss during the consultation [15]. The aim of a QPL is to enhance information provision during consultations, which is one of the six functions of medical communication [16]. By using a QPL, patients are expected to participate more actively during their consultation, for instance by asking more and broader-ranging questions [17]. These improved communication outcomes can lead to the provision of more personally relevant and adequate information from the provider [18] which might result in positive psychological (e.g., lower levels of anxiety) and/or cognitive (e.g., better recall of information) outcomes [1–4].

The effectiveness of using QPLs singly or as part of a larger intervention (from now on both called QPL interventions) has been assessed in several literature reviews [4,15,17,19–22]. However, six new high quality randomized controlled trials on the effectiveness of QPL interventions in oncology have been published recently, and the previous reviews did not consider these studies. Moreover, none of them assessed the effectiveness of QPL interventions in oncology on communication, psychological and/or cognitive outcome measures, while taking the methodological quality of the studies into account. The methodological quality of studies can contribute to the interpretation of
results and effects [23]. Furthermore, all the previous reviews have not explored the characteristics of QPL interventions (e.g., the number and content of questions, and the mode of delivery) and whether the characteristics of QPL interventions might influence their effectiveness. The current systematic review aims to address these gaps in the literature by taking the methodological quality and characteristics of QPL interventions into account.

Method

Inclusion criteria

Studies were included in this systematic review if (a) the study described the effectiveness of a QPL intervention on communication, psychological and/or cognitive outcomes, (b) the study design was a randomized controlled clinical trial (RCT) or a nonrandomized controlled clinical trial (CCT), (c) the study was conducted in an oncology setting, (d) the study was published in English and (e) the study was published in a peer reviewed journal.

Search strategy

A systematic literature search was conducted in electronic databases PsycINFO, Medline, CINAHL and CENTRAL. The literature search was executed in September 2012. The search strategy used the following keywords: (Question Prompt List OR Question Prompt Sheet OR prompt list OR prompt sheet) AND (cancer OR oncology). Additional papers were sought using the snowball method. This means reference list and citation searches were conducted on studies that were included to detect further eligible studies.

Study selection

After the search strategy was implemented by one researcher (KB), two researchers (KB and AL) independently executed a title and abstract screening. There was 90.8% and 96.1% agreement on title and abstract screening, respectively. Disagreements between the authors were resolved through discussion. After the title and abstract screening, two authors (KB and AL) screened full text versions of the selected articles and decided whether the manuscripts met all the inclusion criteria. There was 92.9% agreement between the two authors. When disagreement occurred, a third reviewer (JvW) was consulted. All disagreements were resolved through discussion. The study selection process is shown in Figure S1.

Data extraction

The following characteristics of the included studies were extracted: (a) type of study, (b) study quality, (c) participants (number of participants, age, sex, type of cancer and frequency of having met the provider before patients received the QPL intervention), (d) description of the total intervention (if applicable), (e) outcome measures and (f) significant results regarding the effectiveness of QPL interventions (see Appendix 1 in Supporting information). When data were missing from the included studies, the authors were contacted and asked if they could provide additional information.

Assessment of methodological quality

The methodological quality of the papers was independently assessed by two researchers (KB and AL) using a criteria list from the Cochrane Collaboration Back Review Group [23] consisting of 11 criteria that measure internal validity. The list is shown in Appendix 2 in Supporting information. The Cochrane method is a valid method for assessing the methodological quality of studies and has been used extensively in systematic reviews [21,22,24]. The different items were per study scored with ‘yes’, ‘no’ or ‘unclear’. Studies that received the score ‘unclear’ were later rated as ‘no’. Studies were considered as high quality (HQ) when the study adequately fulfilled six or more out of the eleven criteria. When studies met less than six criteria, they were considered as low quality (LQ). Criteria G (‘were co-interventions avoided or similar?’) cannot be decisive in determining LQ of an article, so when a study met five criteria and criteria G was not met, the study was also rated as HQ. Disagreements between the authors were resolved through discussion. If disagreement persisted, a third reviewer (JvW) was consulted.

Review the effectiveness of Question Prompt List interventions

It was not possible to pool the data of the included studies because of the diversity in the features of the interventions and outcome measures. Therefore, a best evidence synthesis (BES) as proposed by Tulder et al. [23] and adapted by Steultjens et al. [25] was performed. The BES was performed by assigning various levels of evidence to the effectiveness of an intervention. The BES takes into account the methodological quality, design and method of a study, and conclusions are based on significant results. The criteria for a BES are shown in Appendix 3 in Supporting information. A sensitivity analysis was conducted to establish whether the results of the BES were sensitive to changes in the way the methodological quality was assessed. In order to conduct the sensitivity analysis, the BES was repeated in two different ways: (a) LQ studies were excluded and (b) studies were rated HQ when at least four (instead of six) of internal validity criteria were met. The results of the altered synthesis in the second BES were then compared with those of the first BES.

Gain insight into the characteristics of Question Prompt List interventions

The characteristics of QPL interventions were analyzed via five categories: the mode of delivery, the number of questions, the content of questions, at what time the QPL
intervention was delivered to the patient and the intervention components of the QPL interventions. In addition, it was documented whether, if applicable, the control group received any interventions to control for attention. Appendix 1 in Supporting information gives an overview of all the included QPL interventions and their characteristics.

Explore the relation between the characteristics and the effectiveness of Question Prompt List interventions

The results of the BES were used to explore if there was a relationship between the characteristics of the QPL interventions and their effectiveness. When studies reported significant results of the use of QPL interventions on communication, psychological and/or cognitive outcomes, the characteristics of these interventions were compared to explore whether there were similarities that could explain the effectiveness. Furthermore, we explored whether the characteristics of those interventions that were effective were not incorporated in the interventions that were not effective. Thus, a relation between the characteristics and effectiveness is suggested when effective studies had characteristics that ineffective studies did not have.

Results

Study selection

After the database search in PsycINFO, Medline, CINAHL and CENTRAL, and the snowball method search were completed, all duplicate results were removed. Based on the title and abstract screening of the remaining hits (n = 120), 82 references were excluded for not meeting all of the inclusion criteria. The full text content of the remaining 38 articles was then screened. This resulted in the exclusion of another 22 articles, leaving 16 articles that met the inclusion criteria. Two out of those 16 articles were generated via the snowball search. Main reasons for exclusion of articles were as follows: the study design was not a RCT or CCT (n = 15), no QPL was used (n = 4) and participants were not cancer patients (n = 3). Figure S1 shows the selection process.

Study characteristics

The main characteristics of the included studies are described in Appendix 1 in Supporting information. Across studies, the average age of participating patients was 59.3 years. The type of cancer was diverse across studies with breast cancer being the most reported. In 13 out of 16 studies [1,2,10,12,26–33,37], cancer patients were seeing their provider regarding treatment for the first time. In two studies, patients had met their provider before [35,36], and in one study [34], it was not clear how many times patients had met with their provider when they received the QPL intervention.

Table 1. Study quality table

<table>
<thead>
<tr>
<th>Study</th>
<th>Validity criteria met</th>
<th>Study quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>RCT</td>
<td>ab.c.f.h.i,j</td>
<td>High</td>
</tr>
<tr>
<td>Brown et al. (10)</td>
<td>a,c,h,j</td>
<td>Low</td>
</tr>
<tr>
<td>Brown et al. (2)</td>
<td>a,b,c,j</td>
<td>High</td>
</tr>
<tr>
<td>Bruera et al. (27)</td>
<td>a,c,d,e,h.i,j</td>
<td>High</td>
</tr>
<tr>
<td>Butow et al. (29)</td>
<td>c,g,h,j</td>
<td>Low</td>
</tr>
<tr>
<td>Butow et al. (28)</td>
<td>a,c,d,h,i,j</td>
<td>High</td>
</tr>
<tr>
<td>Clayton et al. (36)</td>
<td>a,c,f,h,j</td>
<td>High</td>
</tr>
<tr>
<td>Davison &amp; Degner (30)</td>
<td>a,b,c,h,j</td>
<td>High</td>
</tr>
<tr>
<td>Davison &amp; Degner (34)</td>
<td>a,b,c,g,i</td>
<td>Low</td>
</tr>
<tr>
<td>Gattellari et al. (12)</td>
<td>a,f,h,j</td>
<td>Low</td>
</tr>
<tr>
<td>Hacking et al. (31)</td>
<td>a,b,c,g,h,i,j</td>
<td>High</td>
</tr>
<tr>
<td>Lim et al. (32)</td>
<td>a,b,c,h,i.j</td>
<td>High</td>
</tr>
<tr>
<td>Sepucha et al. (33)</td>
<td>c,h,i,j</td>
<td>Low</td>
</tr>
<tr>
<td>Shirai et al. (37)</td>
<td>a,b,c,h,i,j,k</td>
<td>High</td>
</tr>
<tr>
<td>Smets et al. (35)</td>
<td>a,c,h,i,j</td>
<td>High</td>
</tr>
<tr>
<td>Van Weerl et al. (1)</td>
<td>a,b,c,h,j,k</td>
<td>High</td>
</tr>
</tbody>
</table>

Please note that the letters that correspond to the validity criteria are explained in Appendix 2.

Methodological quality

In this systematic review, 15 RCT studies and one CCT study were included. A total of 11 out of 16 studies were assessed as HQ studies. Table 1 shows the quality ratings per study.

Effectiveness of Question Prompt List interventions

Based on the BES (Appendix 3 in Supporting information) of all the different outcomes of the included studies, conclusions can be drawn for the effectiveness of QPL interventions on communication, psychological and/or cognitive outcomes.

Communication outcomes

Question asking

In six out of the 16 studies, the number of questions that were asked by the patients was reported. Four studies, all identified as HQ studies [1,28,35,36], reported that the number of questions asked during consultation was significantly higher in the intervention group. This indicates evidence for the effectiveness of QPL interventions in enhancing questions asking. Two other studies, one HQ [27] and one LQ [29], reported that the number of questions asked in the consultation was not significantly influenced by the use of a QPL intervention.

Length of consultation

The length of the consultation was reported in five studies [1,2,27,28,36]. Three HQ studies [1,27,28] indicated that the length of the consultation did not significantly differ between the intervention group and the control group. Two HQ studies [2,36] reported significant changes in consultation length. The first study [2] found that the length of a consultation became significantly shorter when patients used a QPL and providers endorsed the QPL. In contrast, the second
Psychological outcomes

Satisfaction with the consultation
Satisfaction with the consultation was the most reported psychological outcome. It was measured in 12 out of the 16 studies. In all of these studies, consisting of seven HQ studies [2,27,28,32,35–37] and five LQ studies [10,12,29,33,34], QPL interventions did not influence patients’ satisfaction with the consultation. All studies found high levels of satisfaction with the consultation in both the intervention and the control groups, and there were no significant differences between these groups. Thus, there is no evidence that the use of a QPL intervention influences satisfaction with the consultation.

Anxiety
Nine studies measured whether a QPL intervention influenced patients’ anxiety. Five studies, consisting of two HQ studies [31,36] and three LQ studies [10,12,29], reported that QPL interventions did not influence patients’ anxiety. Furthermore, two HQ studies [30,32] concluded that the use of QPL interventions significantly reduced patients’ anxiety at follow-up. In the first study [30], the anxiety of patients in the intervention group, receiving a QPL, an information package and an audiorecord of the medical consultation, was reduced at 6-week follow-up as compared with the pre-test measure (i.e., before receiving the intervention). In the second study [32], anxiety of a subgroup of patients, receiving an isolated QPL, was significantly more reduced between the initial surgery consultation (on which the QPL intervention was focused) and 1 day prior to the surgery as compared with the control group, who received usual care. Moreover, in the entire sample, anxiety was significantly reduced in the intervention group as compared with the control group at the first postoperative follow-up consultation.

Two other studies described the effects of short-term anxiety. One HQ study [28] reported that the anxiety of patients in the intervention group, receiving a cancer consultation preparation package including a QPL, significantly increased after the patients received the QPL intervention (but before consultation), as compared with the control group, receiving a control booklet. Immediately after the consultation and 1 month later, no significant differences between the intervention and the control group were found. In another HQ study [2], three groups of patients were compared: one group received a QPL, the second group received a QPL and the oncologist actively endorsed and systematically reviewed the QPL, and the control group received usual care. Immediately following the consultation, patients with a QPL alone were significantly more anxious than patients in the other two groups. There were no differences in anxiety levels between the groups at 1 week post-consultation measurement.

These findings provide evidence that QPL interventions can decrease anxiety at follow-up (i.e., a few weeks after the provision of QPL interventions). However, there is also limited evidence that QPL interventions can increase patients’ anxiety shortly after exposure to the intervention, as was found immediately before the consultation [28] and immediately after the consultation [2].

Depression
Three HQ studies [28,30,31] included depression as an outcome measure. These studies found no differences in levels of depression between the intervention group and the control group, indicating there is no evidence that a QPL intervention can influence depression.

Psychological adjustment
Psychological adjustment was measured in two LQ studies [10,29] and one HQ study [31]. These studies concluded that a QPL intervention did not influence cancer patients’ psychological adjustment. Thus, there is no evidence that a QPL intervention can influence psychological adjustment.

Psychological distress
One HQ study [26] investigated the effect of QPL interventions on psychological distress. Aranda et al. [26] concluded that their intervention slightly improved psychological distress, but this result was not significant. This finding suggests there is no evidence that a QPL intervention can influence psychological distress.

Cognitive outcomes
Recall of information
Recall of information was measured in four studies [1,2,12,29]. Two LQ studies [12,29] reported that the use of a QPL intervention did not influence recall of information. Two HQ studies [1,2] reported a significant effect from the QPL intervention on recall of information. One study [1] found a significant effect on recall in two out of six sub-categories. Another study [2] found an improvement in recall of information when patients received a QPL intervention that was actively endorsed by their provider. These findings indicate evidence for the effectiveness of a QPL intervention on recall of information.

Effects of isolated Question Prompt Lists
After singling out the results for studies that tested an isolated QPL intervention (four HQ studies [27,32,35,36] and one LQ study [29]), BES indicated evidence for a positive effect of an isolated QPL on question asking. This result came from two HQ studies [35,36]. Further, there is limited
evidence that an isolated QPL can positively influence anxiety at follow-up. This result came from one HQ study [32].

Sensitivity analysis

When the BES was repeated using the principles that LQ studies were excluded and studies had to meet four instead of six criteria of internal validity, the results remained the same. This indicates that the results are robust.

The characteristics of Question Prompt List interventions

Mode of delivery

In 11 out of the 16 articles [1,2,10,12,27–29,32,35–37], a hardcopy QPL was given to the patients. In three studies [30,31,33], patients were asked what their information needs were and a researcher, a so-called navigator (i.e., a trained research assistant) or a provider created a QPL based on patients’ answers, which they later gave to the patient. In one of these studies, the provider received the QPL before the consultation, and the navigator joined the patient in the consultation [31]. One study [34] used a computer program to create the QPL. In this study, patients received assistance from the computer program in identifying their information needs. The computer program generated statements that the patients could select. Patients could then print this QPL and take it with them to consultation. Another study [26] used a QPL on a chemotherapy educational DVD. The questions that patients could ask in the consultation were shown on the DVD in order to educate patients on how they could ask questions.

The number of questions on the Question Prompt List

Of the 16 studies, 10 studies [1,2,10,27–29,32,35–37] reported the number of questions on the QPL that could be selected by patients. The number of questions ranged from 10 to 112 questions with a mean of 32.7 questions. In two studies, the number of questions on the QPL was not reported [12,26]. In four studies [30,31,33,34], the QPL was individually created by the patients with assistance. Therefore, the number of questions on these QPLs varied. None of these studies reported how many questions were included in the final lists.

Content of questions on the Question Prompt List

The majority of QPLs were framed with instrumental questions regarding patients’ disease and treatment. Nine studies [1,2,10,12,26–29,37] used a QPL with general questions (e.g., ‘What kind of treatment do I need?’ and ‘What kind of symptoms will this cancer cause?’). Those questions were applicable to different types of cancers at any stage of the disease. Three studies reported the use of a QPL for a specific patient group. Clayton et al. [36] used a QPL with specific questions for patients seeing a provider in palliative care (e.g., ‘How long am I likely to live?’). Lim et al. [32] and Smets et al. [35] used a QPL specific to the surgical setting (e.g., ‘Is this surgery going to improve my change of survival?’). In four studies, the QPLs were individually created with the help of a researcher, a navigator or a provider [30,31,33] or by a computer program [34]. In these four studies, it was unknown what kind of questions patients asked and whether these questions had an instrumental character. In two studies [31,33], patients were also asked to write down possible concerns they were experiencing. These QPLs might partly be framed with affective questions (i.e., concerns) rather than instrumental questions.

Moment of delivering the intervention

Nine studies [1,10,12,30–34,37] reported that the QPL was given to the patient before consultation but did not give a specific time indication. Four studies described that the QPL was delivered directly before the consultation and specified the exact time that patients had to read the QPL. Times that were reported varied from 10 min [29], 15 min [35], 15–20 min [2] to 20–30 min [36]. Two studies reported that patients received the QPL at least a day before the consultation. Butow et al. [28] sent a QPL together with a consultation preparation package to patients 48 hours before their consultation. Aranda et al. [26] sent their preparation package with a QPL to patients 1 to 7 days prior to consultation. One study [27] did not report anything about time of delivery.

Intervention components

In five out of 16 studies [27,29,32,35,36], the QPL was tested in isolation, without other intervention components. In 11 out of the 16 [1,2,10,12,26,28,30,31,33,34,37] studies, the QPL was combined with other intervention components. Seven studies [1,2,10,12,30,31,33] combined the QPL with an interpersonal communication intervention: three interventions focussed on the patient, three interventions on the provider and one study on both the patient and the provider. The three interventions that focussed on patients’ empowerment [10,30,33] consisted of a coaching session. In these sessions, a researcher or a provider explained how to use the QPL or discussed which questions were useful for the patient to ask. The three interventions [1,2,12] that focussed on the provider combined providers’ interpersonal communication skills with the use of a QPL. Brown et al. [2] and Gattellari et al. [12] manipulated provider endorsement of the QPL in their intervention. Providers were randomized to a group that had to endorse the QPL or to a group that did not have to endorse the QPL. Furthermore, Brown et al. [2] also trained their providers in using a protocol about QPLs in which the importance of question asking and reassuring patients about question asking was addressed. In the third intervention [1], a communication skills training for nurses was developed. One of the key elements of the training was how to use the QPL (a preparatory booklet including a QPL) during an educational chemotherapy consultation with
older cancer patients. In the intervention that focused on both the patients and the providers [31], patients received a coaching session either in person or over the phone. A navigator helped patients to compile a QPL based on their own questions and concerns. The QPL was then given to both the patient and the provider. The navigator joined the patient in the consultation to encourage both the patient and the provider to address the QPL.

In one study, the QPL was part of a tailored computerized intervention [34]. Patients created the QPL themselves on a computer. In the studies of Aranda et al. [26] and Butow et al. [28], the QPL was a part of a consultation preparation package. Both studies included booklets and brochures about cancer in the package. In one study [37], a QPL was combined with an information sheet about the hospital.

Control group interventions

In six out of the 16 studies, the control group received additional interventions to control for attention. In four studies [27,28,30,37], patients received written materials consisting of information about their disease [27,30] or the hospital/clinic [28,37]. Two studies [26,33] provided their control group with a verbal information session. In one study [26], nurses facilitated an educational session about chemotherapy. Sepucha et al. [33] used a productive listening session for their control group. In this session, researchers prompted patients to talk about their experiences regarding their disease and actively listened to the patients’ story.

Exploring the relation between the characteristics and the effectiveness of Question Prompt List interventions

For three QPL intervention characteristics (i.e., the mode of delivery, the moment of delivery and the content of the questions), there were no indications that they influenced the effectiveness of the intervention. Results did suggest that the number of questions on a QPL and whether the QPL was combined with another intervention component were related to the effectiveness of the interventions. One HQ study, using a QPL consisting of 112 questions [36], found a significant increase of consultation length. There were no other studies that incorporated a QPL with so many questions (i.e., the second largest QPL consisted of 53 questions and the mean number of questions was 32.7). This suggests that a QPL with a large amount of potential questions lengthens the consultation. Results also suggest a relation between QPLs that were combined with provider training and their effectiveness on recall of information. Studies that had no effect on recall of information consisted of QPLs that were not combined with another intervention element [29] or only combined with provider endorsement and not provider training [12]. The two studies [1,2] that reported positive effects on recall of information were both part of a larger intervention focusing on provider training. In these studies, providers [2] and nurses [1] were trained to address the QPL and to emphasize question asking during the entire consultation contrary to a study [12] wherein a QPL was combined with provider endorsement only at the end of the consultation.

Discussion

This systematic review examined the methodological quality of QPL intervention studies to determine the effectiveness of QPL interventions. Eleven out of 16 studies were found to be of high quality. Results of the BES showed that there is evidence that QPL interventions can improve communication outcomes (i.e., question asking) and that QPL interventions can positively influence psychological outcomes (i.e., anxiety at follow-up) and/or cognitive outcomes (i.e., recall of information).

This systematic review also aimed to gain insight into the characteristics of QPL interventions and whether the effectiveness of QPL interventions might be related to their characteristics. When reviewing the included articles, it was discovered that there is no standard design for a QPL intervention. The number of questions, type of questions and the moment that patients were exposed to the QPL intervention varied. Some relationships were suggested between the characteristics of QPL interventions and their effectiveness. A higher amount of questions seemed to increase consultation length. Furthermore, the two studies [1,2] that reported positive effects on recall of information were both studies where a QPL was combined with a provider training on addressing QPLs during a consultation and stimulating question asking. A study that incorporated provider endorsement only at the end of the consultation without provider training [12] found no effect on recall of information. This implies that QPLs might be more effective in enhancing recall of information when the provider receives training in how to endorse them and how to encourage patients to ask questions from it. Although it is uncertain in which parts of the consultations the providers in the effective studies [1,2] addressed the QPL, it could be that QPLs need to be addressed during the entire consultation rather than at the end. Future research could elaborate on this by measuring differences in effects of QPLs when they are addressed during different time points in the consultation.

The two studies that had an effect on recall of information consisted of two intervention components (i.e., a QPL and provider training). When interventions are delivered in two different components, for example a written QPL combined with interpersonal communication, a so-called synergy effect can occur [38–40]. A synergy effect means that two intervention components combined reinforce each other, and their combined effect exceeds the sum of their individual effects [39,40]. The synergy effect has mainly been researched in a marketing
settings [39], but a recent study [38] suggested that it can be effectively used in health communication. It is therefore possible that a synergy effect emerged in the studies that found significant results on patients’ recall of information.

This systematic review provides a recent overview of the QPL intervention literature. Since the review by Dimoska et al. [15], six new HQ RCT studies have been published [1,26,31,32,35,37]. After conducting a BES, some of these studies [1,32] contributed to the evidence of QPL interventions on other outcomes than communication outcomes (i.e., reduced levels of anxiety at follow-up [32] and improved recall of information [1]). These results are promising but should at the same time be interpreted with caution. Although there is evidence for the effectiveness of QPL interventions on recall of information, one of the two studies that contributed to this level of evidence [1] only found limited effects on recall of information. A similar remark can be made by the results from the BES on anxiety at follow-up. In one study [32], anxiety decreased significantly more between baseline and follow-up in the intervention group than in the control group. However, at follow-up, the reduction in the intervention group was significantly higher than in the control group because of higher baseline levels of anxiety in the intervention group. Additional research on psychological and cognitive outcomes is therefore recommended to further confirm these findings.

According to the results of the BES, there was no evidence for the effectiveness of QPL interventions on other psychological outcomes such as satisfaction with the consultation, depression, psychological adjustment and psychological distress. The lack of effect could possibly be explained by the observation that QPLs mainly consist of instrumental questions. Bensing and Verhaak [7] have argued that patients can have two kinds of information needs: (a) cognitive (instrumental) information needs where patients want to understand what is happening to them and with their disease and (b) affective information needs where patients want to feel understood by their provider and feel the need to express their worries and concerns. Instrumental information needs can be fulfilled when instrumental questions are asked, and affective information needs can be fulfilled when concerns are expressed [41]. The expression of a concern is a direct way of gathering information that is needed to deal with fears and worries that patients have [41,42]. Therefore, it is possible that a QPL framed with concerns instead of questions could improve psychological outcomes such as depression, psychological adjustment and psychological distress. It is recommended to investigate this in future research.

It was notable that there is a lack of studies that provide the QPL in another mode than hardcopy. Only two studies [26,34] provided the QPL in a different mode. One study used a computer program that the patient could use to create their own QPL [34], and one study provided the QPL on a DVD [26]. A recent study [43] has explored whether cancer patients have different media preferences and found that different psychological factors such as the coping style of a patient influence their media preferences. When an intervention is tailored to patients’ specific needs including their media needs, its effectiveness can increase. Therefore, future studies could also explore this for the mode of QPLs, for example by investigating whether mode-tailed QPLs are more effective than QPLs in a standard mode.

The possibility that publication bias occurred during the study selection process is a limitation of this study. Moreover, although a systematic literature search and a snowball method search were conducted, some studies that might have met all the inclusion criteria could have been missed in the search.

Conclusion

In this systematic review, the effectiveness of QPL interventions on communication, psychological and cognitive outcomes was assessed. Overall, QPL interventions were found to be effective in enhancing the number of questions asked during consultation. There is also evidence that QPL interventions positively influence anxiety at follow-up and recall of information. There is no evidence for the effectiveness of QPL interventions on patients’ satisfaction, depression, psychological adjustment and psychological distress. Future studies can continue examining how to improve the effectiveness of QPL interventions by testing at which time points during a consultation it is most effective for a provider to address a QPL, by designing QPLs that emphasize affective communication and by tailoring the mode of QPLs to patients’ preferences.

References


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Supporting information

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