

Factors affecting patient's decision-making about treatment for cancer: a literature review.

Abstract

Decision-making about cancer treatment is complex. This literature review explores factors that impact on patients' decision-making about treatment.

Results were returned in MEDLINE, British Library, PsycINFO and Science Direct databases. These were filtered, using a PRISMA flowchart and inclusion and exclusion criteria applied. Six original papers, assessed as high quality using Critical Skills Appraisal Programme checklists, were reviewed. Data was collated and thematically analysed.

Four themes were developed: communication and information giving, children and family influences, hope and treatment toxicities. These themes demonstrate the complexity of factors that influence decision-making about treatment and reinforce the importance of nurses, particularly clinical nurse specialists, using effective communication skills to make shared decision-making a reality.

Developing a strong therapeutic relationship and getting to know patients over the course of their cancer journey, using communication tools, enables nurses to recognise and respond to emotional cues from patients and to start sensitive conversations about factors affecting them. Facilitating information sharing around treatment decision-making enhances patient's experience by supporting their autonomy.

Key words

Cancer treatment. Decision-making. Communication and information giving. Children and family influences. Hope. Treatment toxicities. Clinical Nurse Specialist.

Introduction

Shared decision-making is an essential aspect of clinical practice (NICE 2021, NHS 2021), encouraging communication about values that individuals hold and things that are important to them, and emphasising empowerment for informed choice. Medical decision-making is “the process by which a diagnosis or treatment plan is formulated from the available test information, often with incorporation of known patient preferences” (Whang 2013), based on probable outcomes of the interventions available. Decision-making about treatment relies on effective communication between health care professionals and patients, to ensure informed consent is obtained. Treatment decision-making for cancer is complex and is a common point of communication breakdown (Thorne et al. 2013). Key decisions are required early on when emotionality is high and relationships are new and when the amount of information is overwhelming (Roeland et al. 2014).

There were 363,484 new cases of cancer diagnosed in the UK between 2015-2017 (Cancer Research UK 2020). Treatment options vary according to cancer type and the stage at diagnosis, so can be confusing. Furthermore, individual factors have an influence on treatment decisions and can change at different stages of the cancer journey, from diagnosis to palliative care. Whilst nurses are required to facilitate empowerment of patients (NMC 2018), Mahmoodi and Sargeant (2019) suggest that in practice, shared decision-making is more often rhetoric than reality. It appears straight-forward to support decisions based on facts about diagnosis and treatment outcomes alone, but the complex interplay of individual factors has the potential to threaten shared decision-making.

This literature review analyses factors affecting decision-making around cancer treatments, helping nurses to understand and consider these when providing information to patients for the purposes of informed consent.

Method and search strategy.

The research question “what factors impact decision-making around cancer treatment” was developed using the ‘PEO’ model (see table 1). Precisely focused search terms and synonyms (see table 2) were used, alongside Boolean logic and truncation to maximise search results.

Table 1. Developing the research question

P	Patients with cancer
E	Decision-making about cancer treatment
O	Experiences and feelings

Table 2. Search terms

Patient AND oncology OR cancer; information; treatment AND decision-making OR choice; informed consent; experience
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A total of 362 results were returned in MEDLINE, British Library and Science Direct databases. These were filtered using a PRISMA flowchart (Moher et al. 2009) and inclusion/exclusion criteria applied (see table 3). This resulted in 41 papers being read in full to determine their relevance for inclusion. Ultimately, six original papers that were clearly focused on the question, were systematically analysed using the relevant Critical Skills Appraisal Programme checklist (CASP 2018). All six were rated as excellent using CASP analysis, so were included in the review.

Figure 1: PRISMA flowchart



PRISMA 2009 Flow Diagram

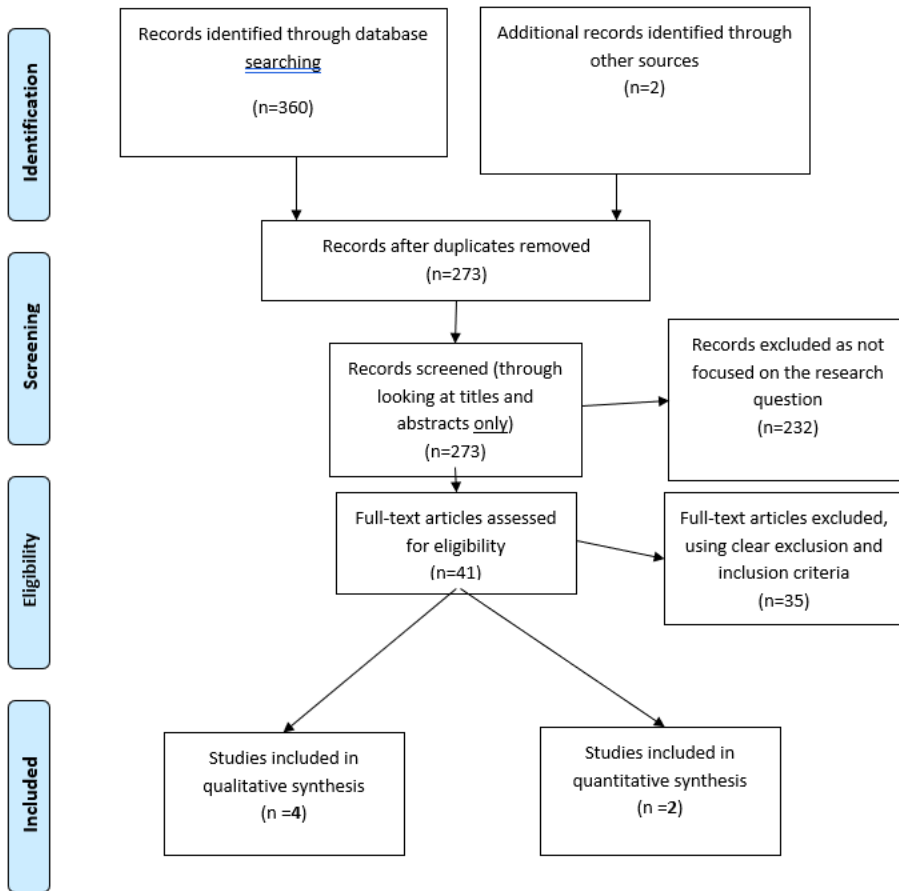


Table 3. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Full text	Not adult patients
English language	Not focused on treatment decision-making
Peer reviewed primary research	
Dated 2010-2020	

Data from the studies were plotted into a table (see table 4), enabling the researcher to become familiar with them and to search for themes within them (Braun and Clarke 2013). Themes were tested within group supervision through presentation to, and dialogue with an academic supervisor and final year student nurse peers. Four themes were discovered: communication and information giving, children and family influences, hope and treatment toxicities. These provide a framework for the discussion below.

Table 4: Summary of research papers reviewed

Authors, date and title	Sample	Design and method	Data Collection	Results
Alifrangis, C, et al. (2011)	125 in/out-patients at a UK cancer centre	Quantitative.	Patient questionnaire.	<p>96 questionnaires returned</p> <p>66% recalled being given a prognosis</p> <p>61% had asked to discuss prognosis</p> <p>31% of patients access Internet information and 7% of patients sought information from other patients</p> <p>90% of patients felt they received clearest information from their physicians</p> <p>FMs, for most patients, was the most important support</p> <p>98% patients willing to accept considerable toxicities for a 5-year extension to lives and 89% would accept treatment for a 3-month extension to life.</p>
Sterba, K., et al. (2013)	Convenience sample - 26 patients with stage 4 colorectal Cancer	Qualitative.	30-90 minute recorded semi-structured interviews by telephone.	<p>Physical QOL Current or anticipated symptoms and functioning were considered versus potential impact of treatment on valued activities.</p> <p>Psychological Quality of Life Physicians often used numbers or statements about probability that</p>

				<p>caused uncertainty or were inherently uncertain. Whilst 'every case is different' they had hope that they would be one of those who "beat the odds."</p> <p>Hope was prevalent as participants tried to remain positive - linked to personal resolve and sense of control - "I am fighting this".</p>
Check, D. et al. (2017)	42 patients, with advanced cancer, who were parents.	Qualitative.	Semi-structured interview.	<p>29/42 said having children affected their choices</p> <p>10/42 reported that having children did not influence treatment decision-making</p> <p>27/42 wanted to extend life to maximise time with children</p> <p>20/42 said children's age affected decision-making (those with younger children wanted to maintain parent functionality)</p> <p>Tension between quality and quantity of life. Life extension and parental functioning as competing priorities</p>
Lidsaar-Powell, R., et al. (2016)	30 adult patients with cancer; 33 adult family members who had attended consultations,	Qualitative.	Semi structured interviews.	<p>Three themes:</p> <p>FMs involved in the decision-making process through information exchange, discussion of choices and preferences</p> <p>Many FMs reported agreeing</p>

	10 oncology nurses and 11 oncologists.			<p>patients decisions. The patient had the final say over treatment.</p> <p>Four stages – no family influence; family influence through provision of emotional and informational support; shared patient and family involvement; and dominant family influence.</p> <p>Balance of patient authority with the rights of the family in decision-making (since treatment affects them, particularly around fertility and young family).</p> <p>Factors influencing family involvement: Involved FMs often middle aged, of a different generation to the patient, female, well-educated and possessed professional medical/health experience.</p> <p>Relationship factors. FMs were more involved in decision-making when they had a strong and close relationship with the patient.</p>
Walczak, A., et al. (2016)	110 patients with advanced incurable cancer.	Parallel randomised controlled trial design. Quantitative data collection.	Baseline questionnaire Recording of a consultation Follow-up questionnaire after 1 month QOL and communication scales	<p>Consultation data showed more questions and cues to discuss future care in CSP group</p> <p>No statistically significant data about communication efficacy</p> <p>High satisfaction with the CSP</p>
Smith, S., et al. (2017)	21 adult patients	Qualitative.	Semi-structured interview	Patients perceived decisions about treatment as consenting to

	receiving radiotherapy for cancer			<p>Oncologists' recommendations.</p> <p>Some participants felt they weren't given an option to refuse treatment.</p> <p>When professionals disagreed, the patient felt burdened regarding the decision, seeking a third opinion.</p> <p>The overriding need to survive influenced decisions about treatment.</p> <p>Some participants justified treatment for improving QOL.</p> <p>Having treatment was a way to avoid decisional regret in the future.</p>
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Findings:

Communication and information giving

Communication and information giving reflects a significant factor that impacts on treatment decision-making. In their quantitative study exploring communication and quality of life with 125 cancer patients, Alifrangis et al. (2011) noted that whilst some patients and family members (FMs) accessed Internet information, 90% (n=113) of participants relied on their oncologist's information for treatment decision-making. Only 68% (n=85) of patients recalled asking to discuss prognosis, a key factor in decision-making, whether the treatment is intended to cure disease, reduce symptoms and/or extend life (Sterba et al. 2013, Laidsaar-Powell et al. 2016, Check et al. 2017, Smith et al. 2017).

Examples across the studies highlighted patient's feelings that they were not given a choice over treatment, either because their consent was confirming agreement with the oncologist's recommendations (Sterba et al. 2013, Laidsaar-Powell et al. 2016, Check et al. 2017, Smith et al. 2017) or their personal situation removed any sense of choice from them (Sterba et al. 2013, Check et al. 2017). Particularly when they had young children, treatment was considered the only choice.

The way that information was, or was not delivered, impacted on how empowered patients felt about decision-making (both having treatment, or not having treatment). One participant in Smith et al's (2017) study noted how 'not having treatment' was not presented as an option. He felt that justifying a wish not to have treatment would appear to question the oncologists advice. Patients commonly sought information for themselves, analysing its match with advice from oncologists, having greater confidence in their choices when information was consistent (Alifrangis et al. 2011). Most patients had faith in information from oncologists, however more patients sought information from the Internet (35% n=44) than from nurses (8% n=10).

A randomised control trial to assess the impact of a communication support programme (CSP) on treatment decision-making was undertaken with 110 patients with advanced cancer (Walczak et al. 2017). Of 363 patients invited 110 participated, with 61 randomised to CSP intervention and 49 to the control group. Results were returned by 39 patients in the CSP group and 40 in the control group. After delivery of the CSP intervention, focused on communication skills and delivered by two specially trained oncology nurses, consultation data was analysed. Both groups used 'cues' to discuss future care in consultations but the CSP group asked more 'questions' about future care than the control group. Whilst the difference between the groups was not statistically significant, the CSP was evaluated very positively by patients, who felt empowered to ask questions after engaging with it.

Children and family influences

Children and family influences are a central factor in treatment decision-making. Children were influential, whether the patient was a parent already, or wished to become a parent. The wider family also influence treatment decisions, whether directly or indirectly, in relation to caring roles and responsibilities of the patient and preferences of the family members (FMs).

The experience of treatment decision-making for parents was explored with 42 patients with advanced cancer, all of whom had at least one child aged under 18 years (Check et al. 2017). Data revealed that life extension and parental functioning were competing priorities, alongside quality and quantity of life. For some, having children meant there was no choice about treatment. Whilst 29 participants reported that having children affected their choices, ten said that it did not influence their decision. Participants with younger children (n=20) considered the impact on parental functionality when making treatment decisions. Extending life to maximise time with children was important for 27 participants. This data illustrates some of the tensions in decision-making, reinforcing the importance of understanding the individual patient's situation when discussing treatment options.

Laidsaar-Powell et al. (2016) reveal the complex influences of FMs in treatment decision-making. Interview data from 30 adult patients with cancer, 33 adult FMs who had attended consultations, ten oncology nurses and 11 oncologists revealed three themes. These are family involvement over five stages (pre-clinic, three stages in clinic and post-clinic); attitudes towards family involvement (balancing patient authority with the rights of the family); and factors influencing family involvement (patient, family, cultural and relationship). FMs were key in information exchange and deliberation about treatment preferences, with patients in most cases making treatment decisions. Some dominant FM influence was observed in clinic consultations, but the healthcare professionals noted that patients appeared comfortable with family control. A minority of FMs dominated the consultation, leaving little room for patient choice.

Some FMs felt they deserved to be involved in decision making because cancer diagnosis and treatment also affects them (Laidsaar-Powell et al. 2016). Patients felt it was important to include partners in decisions affecting fertility and sexuality, or when they had young children. FMs were more actively involved when they were middle aged, of a different generation to the patient (particularly if the patient was an elderly parent), female, well-educated and with professional health experience. Families who demonstrated close relationships were more involved in decision-making. The data reveal the complexity of FM involvement and influence in treatment decision-making, reinforcing the importance of understanding the individual patient's situation when discussing treatment options.

Hope

Hope, as a factor that influences cancer treatment decision-making, is focused on different outcomes at different stages of the cancer journey (cure in the early stages, extended life in advanced stages and hope of reducing the physical effects of cancer throughout). Hope for life extension is linked to family involvement and parenting but is not dependent on a patient having children. Alifrangis et al's. study of communication and quality of life (2011) featured hope as a factor influencing treatment decision-making. Almost all participants (98% n=123) would accept considerable treatment toxicity for hope for a five-year extension to their life and 89% (n=111) would accept it for a three-month extension to their life. Only a minority would not be prepared to accept a gain of lifespan alone when balanced with the side effects of chemotherapy. The work of Smith et al. (2017), with 21 patients receiving radiotherapy for cancer reinforced that their overriding hope for survival influenced treatment decision-making. Treatment was also justified through hope for improved quality of life, including reduction or resolution of cancer symptoms (notably pain). Receiving treatment enabled hope to persist and in the case of one participant, protected her from decisional regret in the future.

Hope is prominent in the work of Sterba et al. (2013), who interviewed 26 patients with stage four colorectal cancer about their coping strategies. Patients with a primary diagnosis of colorectal cancer described making treatment decisions based on their hope of cure, whilst those diagnosed when their cancer was advanced described how hope for more 'time' before death influenced their decision-making. Treatment decisions also reflected hope for relief from physical cancer symptoms (notably pain). Even when patients received uncertain predictions from oncologists regarding responses to treatment, they had hope that they would be 'one of the ones' who did respond (Sterba et al 2013).

Treatment toxicities.

This theme relates primarily to the immediate toxicities of cancer treatment. Participants in Sterba et al's (2013) study discussed how current or anticipated symptoms and functioning informed treatment decision-making. Sometimes there was 'no choice' since the effects of the cancer were so profound. Accepting treatment might avoid decisional regret if cancer progresses without it, but toxicities, individual to each patient, can be severe. One participant who experienced such severe plantar fasciitis that she couldn't walk and therefore participate in social activities would have contemplated the treatment decision much more fully with prior knowledge of aggressive the toxicities would be (Smith et al 2017).

Long-term function, particularly around fertility or sexuality, is balanced against short term treatment toxicities. One participant in Smith et al's (2017) study justified his choice for radiation therapy rather than surgery, since it had a significantly higher chance of him maintaining his sexual function, which was inextricably linked with his identity as a man. Overall, the data reviewed supports patients' choice to have treatment and suffer short term toxicities in hope of a cure or extended life, or relief of prominent symptoms of the cancer. The potential long-term impact of toxicities (i.e. new cancer) was considered low risk in comparison to the short-term benefits at the time of decision-making.

Discussion:

The themes discovered in this literature review reinforce the complex range of factors that influence treatment decision-making for people with cancer and their FMs. Patients need time to adjust to a cancer diagnosis and to collect relevant information before making decisions about treatment, however time can be limited when prompt treatment is recommended to optimise clinical outcomes. The initial stages of cancer diagnosis and treatment decision-making are commonly biomedically dominated. Most patients look to oncologists as their main source of information (Alifrangis et al. 2011), with only 10% of patients seeking information about decision-making from nurses. Within the patient-oncologist relationship, the balance of power lies clearly with the oncologist, with patients describing decision-making as confirming the oncologist's recommendation, removing any feeling of choice (Smith et al. 2017). Patients are understanding of the high stress environment that oncologists practice in, that can foster a sense of emotional distance from them (described as self-protection). The oncologist was distanced from the patient until their confirmation of a curable (as opposed to terminal) diagnosis, when they appeared to become warmer to the patient (Smith et al 2017). Impressions of oncologists being very busy reduces the potential for discussion and information sharing that underpins decision-making, resulting in 'shared decision-making' becoming rhetoric rather than reality (Mahmoodi and Sargeant 2019). For shared decision-making to be reality it is essential to understand the factors that impact on this, decision-making.

Whilst patients may feel there is little choice but to agree with the oncologist's recommendation to achieve the best clinical outcomes, their personal situation also influences the degree of choice they feel they have. Whether these reflect spiritual, psychological or social influences, including parenting status or caring responsibilities, they demand a patient-centred approach to care. Nurses are well placed to develop therapeutic relationships with patients. They learn effective communication skills, self-awareness and emotional intelligence awareness whilst training, that support them to recognise and respond to cues from patients and start difficult conversations. Emotional intelligence skills are key, where nurses act on feelings of discomfort about the emotions of self and others. Nitzky (2018) proposes that therapeutic relationship development is supported by nurses being present when the oncologist explains the diagnosis and treatment options to patients, so that they can support patients to ask questions and translate information from medical jargon. However, whilst nurses are commonly present during

clinic consultations and hear the conversations between the oncologist and patient, the logistics of the clinic system render it difficult to advocate for them in a meaningful way in that moment.

Ethical principles and professional guidance offer a clear imperative for nurses to support informed consent in relation to all aspects of a patient's care, including decision-making (NMC 2018). Patients within Walczak et al's (2017) study did ask more questions about treatment options following a CSP intervention, but this remained limited by the consultation time. Nurses who are present in the consultation can assess patients' understanding of information delivered and observe for cues for further information or questions. Using emotional intelligence to recognise and respond to the cues from patients and their FMs can help patients to feel better prepared for treatment decision-making. If patients and their FMs were offered opportunities to meet with a nurse separately, they would have a further chance to ask questions. Providing information for treatment decision-making requires a high level of knowledge, confidence, skill and courage, to be able to respond to complex questions and to support the patients to make the choice (Baillie 2017). It is not uncommon for patients to seek the opinion of others, including health professionals, about what they would do in the situation (McCarter et al. 2016). Whilst nurses must offer information to support the decision, they cannot make the decision for the patient or 'nudge- them towards a particular option (Fridman et al. 2018), nor pass judgment on the decision that the patient makes (Roeland et al. 2014, NMC 2018). This high-level information sharing is suited to the role of an experienced oncology nurse, ideally a clinical nurse specialist (CNS) (McAllister and Schmitt 2015). The CNS is well informed about the individual's treatment options through multi-disciplinary case conference meetings (Taylor et al. 2019, Wallace et al. 2019), so is well placed to simplify the treatment plan for the patient, to convey all the relevant information and support an informed decision about treatment (Tariman et al. 2016).

When a CNS is in place, they provide a constant for the patient and their FMs throughout the cancer journey, compared to other professionals who are involved episodically (Tod et al. 2015), so the CNS gets to know them over time. Davis (2015) reinforces the importance of understanding the patient and family needs when presenting treatment information. He highlights the benefit of using a tool, such as the

Patient and Family-Centred Care (PFCC) toolkit developed by the Kings Fund, to support a sensitive response to the situation of the patient and their family (The Point of Care Foundation Undated). As the CNS gets to know the patient and family better over time, it becomes easier to initiate difficult or sensitive conversations around individual factors that influence treatment decision-making. In terms of treatment decision-making, the additional time with a CNS gives patients focused time to ask questions and to express individual preferences, resulting in a more individualised approach as they consider their options.

Implications for practice:

Supporting patients with an intervention such as a CSP can facilitate empowerment by helping them to ask questions about treatment options. The CNS is very well placed to share information around treatment decision-making with patients and their families, being involved in multi-disciplinary case-conferences where treatment options are discussed. Offering patients meetings with the CNS supports decision making by facilitating discussion and questions that could not be addressed within the oncologist consultation. Communication tools such as the PFCC can be useful for the CNS, as they support the development of the therapeutic relationship and enable initiation of sensitive conversations.

Core skills around information sharing for decision-making are of benefit across all oncology care settings. The CNS has a powerful opportunity to influence the communication practice of junior/inexperienced nurses, through role modelling, creating practice opportunities including role-play, and developing learning through reflective conversations in and on practice. Oncology nurses, in any context that they connect with cancer patients, can and should apply effective communication skills, recognising and responding to emotional cues and questions to facilitate informed decision-making.

In conclusion, the themes of communication and information giving, children and family influences, hope and treatment toxicities discovered in this literature review demonstrate the complex interplay of factors that impact on treatment decision-making. Communication and information sharing is the area where oncology nurses can have the greatest impact on the patient experience. Effective communication will support development of a therapeutic relationship, leading to knowing a patient and their family well. This understanding supports discussion about individual factors that influence treatment decision-making, including children and family influences, hope and treatment toxicities. The oncology CNS is well placed to provide information around treatment decision-making, being involved in the multi-disciplinary discussions around treatment options and being a constant in the patient's cancer journey, meaning they get to know them well. Tools such as FPCC and CSP can be used to support effective communication between nurses and patients. In addition to modelling effective communication skills with patients, the oncology CNS is well placed to support the development of effective communication skills in junior and/or inexperienced nurses, to enhance the experience of patients across their cancer journey.

Limitations:

Due to the nature of the participant population, there was some data loss due to the poor health and death during the studies. There is a bias towards qualitative data leading to understanding of the factors affecting treatment decision-making, however further evaluation of the impact of interventions to support decision-making would help nurses identify specific ways to influence practice.

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