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The State of the Science: Informing choices across the cancer journey with public health mechanisms and decision processes

ANNETTE F. STREET & DELL HOREY

Faculty of Health Sciences, La Trobe University, Bundoora, Victoria, Australia

Abstract

Health decisions involve sharing information and making choices—even if the choice is to leave the decision to others. The way that information is delivered and understood by consumers across their cancer journey in turn influences the health decisions they take. A public health approach to the cancer journey considers the information needs of individuals and the structures and systems that facilitate the provision of credible and timely information. This paper examines emerging research that takes a public health approach to promote information-sharing and health decisions, identifies information-sharing mechanisms used by providers to facilitate shared decisions and evaluates decision support processes designed to improve information-sharing and self-care events. Evidence is presented to guide future research directions.

Health decisions involve sharing information and making choices—even if the choice is to leave the decision to others. The way that information is delivered and understood in turn influences health decisions. Consumers make health decisions with a range of health care providers, and these choices are influenced by the ideas, values and experiences of their families, colleagues, communities and tribes within a wider health care environment. The primary focus of research into information provision and health decisions in cancer care has been concerned with the kinds of information needed at the patient-provider interface. Within this dyad, patients are provided with the information required to make immediate decisions related to screening, genetic counselling or treatment options. Communication research has led the way in demonstrating the efficacy of shared decision-making [1,2], training oncologists to encourage cancer patients to have as much, or as little, participation in decisions about their care and treatment as desired. Within a shared decision-making approach patient preferences are negotiated [3].

As research into communication becomes more sophisticated, more attention is paid to external factors that influence cancer patients outside the patient-provider relationship. As argued by Watson et al. [4], a range of external factors, such as cancer information services or the experience of supporting another person with cancer, may influence a cancer patient's knowledge and attitudes. Likewise, professionals bring their own set of external factors to patient-provider communication, such as their disciplinary background, level of cancer expertise, and their own experiences with cancer, both personal and professional. These external factors are part of a larger public health environment that includes consumer information gained from the mass media, public debate and health promotion strategies.

In this paper we discuss emerging research into a public health approach to inform health decisions that support self-determination across the cancer journey. Public health initiatives are predicated on informed and health-promoting consumers, but conversely, a more informed public leads to greater expectations of services and providers. A public health approach to the cancer journey considers the information needs of individuals and the structures and systems that facilitate the provision of credible and timely information. To manage such an ambitious endeavour we have identified three key components:

Correspondence: Annette Street, Faculty of Health Sciences, La Trobe University, Bundoora 3086, Victoria, Australia. Tel: +61 3 94791794. E-mail: a.street@latrobe.edu.au

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- examination of emerging research in a public health approach to promote information-sharing and health decisions;
- information-sharing mechanisms used by providers to facilitate information-sharing and shared decisions; and
- decision support processes designed to improve information-sharing and self-care events.

The conceptual shift from a medically-derived understanding of consumers' information needs across their cancer journey to a public health approach, where information is available from many sources, needs to be mirrored in research developments. To date, evidence for the best way to implement information and decision strategies at a public health level is diffuse and concentrated in a few small pockets, such as Advance Care Planning (ACP). Public health research in cancer has been more concerned with local evaluations to demonstrate the acceptability of new interventions, rather than rigorous research to test their effectiveness, long-term feasibility, sustainability or transferability.

The impact of external factors in cancer communication

The term 'cancer journey' is a recent entrant into the lexicon of descriptors of the continuum of care. Like the more familiar terms: *continuum of care*, *continuity of care* and *co-ordinated care*, there is no consensus about definitions or measurements relevant to the 'cancer journey'. Consistent with international evidence [5–7], the Australian Senate Inquiry Report [8] into services and treatment options for persons with cancer entitled *The Cancer Journey: Informing choice*, found the need for information during the cancer journey was the most commonly mentioned unmet need. Four important points about the development of consumer choice and participation in decisions concerning present and future care across the cancer journey were made. First, there is a clear relationship between an informed and empowered health consumer and better cancer care outcomes. Second, there is need for a changed health care environment that supports genuinely interdisciplinary cancer care. Third, consumer choices are dependent on access to credible and timely information that meets their needs to make decisions along their journey. Finally, health care providers need to develop new roles to ensure access to authoritative, nationally consistent evidence-based information on services, treatment options, government assistance and links to appropriate support groups [8]. Despite heavy investment into diverse information resources for consumers and excellent research into communications skills training to develop competent health practitioners [2, 4, 8–12], a gap remains between the information-seeking goals of individuals, their families and communities and the available information resources.

There are a number of explanations for the current situation of unmet information needs, all of which contribute to some degree. For instance, we appear to be missing the mark in terms of the type and range of information people need and the information they are given or can access. It is highly probable that everyone gets some of the information they need for self-care and health decisions at different decision points. Yet, it also seems that many people don't get all the information that they want [13] or the type of information they need; or the information is offered at the wrong time and so is ignored or rejected [14,15].

People are changing—many are better educated, have had more exposure to cancer prevention messages, more exposure to health information, have higher expectations of care and are more likely to have a chronic disease or be a survivor of cancer [16,17]. Lower socio-economic status is generally associated with lower levels of health information-seeking and new socially-contextual methods are espoused [18]. It seems that as people learn more, they want to know more and want more control over their lives [19]. The quantity of available information also presents problems for the consumer. There are issues about the credibility of sources, conflicting information, and the distillation of information relevant to an individual in an environment with an excess of both useful and misleading information [22]. The relative paucity of research on information provision outside the patient-provider exchange means there is a lack of reliable evidence to inform effective and feasible strategies to address broader consumer needs.

A public health approach to cancer information and health decisions

Changes to health care environments are accompanied by changes to the way cancer is understood and managed. Modern public health programs aim to reduce the risks, incidence and mortality of cancer, and improve quality of life for cancer patients [21]. Ideally this is achieved through the systematic and equitable implementation of evidence-based strategies across the continuum of care [22,23]. We can see examples where focused policy and legislative modifications have improved the risk of the whole population through interventions such as sunscreen programs [24] and smoke-free environments [25]. Such approaches are underpinned by government

aspirations that individuals will make health decisions to change their lifestyle and environment to preserve health and reduce the risk of cancer. Yet the impact of these types of behaviour change can take time to appear and there can be a significant lag in building research evidence of benefit.

Another consideration of the explosion of health information now available is that much of it comes from sources outside the provider-patient communication dyad, providing new challenges for researchers. Cancer information is presented regularly on television (science programs, medical soap operas, news and current affairs) and is the subject of popular and serious print media of all kinds [25]. Health information is highly accessible and uncontrolled through the World Wide Web and through electronic-mediated widely accessed technologies such as social network sites like Facebook and Twitter, and through blogs and discussion forums [26].

Thus, reliance on provider information is being replaced by demands for an active role in health decisions, and by active information-seeking [27–29]. Growing awareness of cancer risks means that the information needs of individuals is changing. They may bring questions to providers that can challenge their authority or worldview, such as querying the value of bowel screening or mammograms, effectiveness of PSA counts, or the use of sunscreens. They may ask about exposure to asbestos, counselling regarding genetic risk, prophylactic surgery, or immuno-therapies to prevent cancer-related viruses such as Hepatitis B or Human Papilloma Virus [HPV], or the use of complementary and alternative medicines. They may want to know about refusing or ceasing treatment, end of life care, and physician-assisted suicide [30].

Social determinants also play a part in influencing expectations and choices in health care [27]. Vulnerable groups are least likely to benefit from preventative measures, to receive cancer information and/or have opportunities for self-care because they are subject to a wider range of adverse interrelated social factors [31]. Culture and social cohesion can affect consumer access to information and influence how health information is understood. Other factors include a person's material circumstances, their biological and psychological makeup, health behaviour, or capacity to access health services.

Within these sets of relationships people want different levels of involvement in their health decisions around cancer. Few, if any, people approach every health decision in the same way [32] even though the type of information wanted may not change [33,34]. Multiple factors, including their experiences and the outcomes of previous decisions, affect how people make health decisions. Addressing social determinants in research requires researchers to ensure that vulnerable people are included in communication research.

Mechanisms of a public health approach to cancer and palliative care

There is very little research on public health cancer and palliative care communication initiatives reported in the literature [35] and key questions have been raised about the best ways to develop evidence [36]. Public engagement strategies suggest opportunities to promote broader discussion of cancer and cancer-related issues. An important goal is to achieve more informed consumers and more supportive community that are able to make, and support, difficult decisions along a cancer journey [37]. These strategies are counter-culture in many ways, as they are designed to make currently culturally taboo subjects (loss, grief and dying) part of community discourse. While a number of these initiatives are under investigation, or are reported in the literature [38–40], as yet, researchers do not appear to have found a way to answer some critical research questions needed to articulate the necessary strategies and level of engagement required to ensure ongoing sustainability.

In Australia, compassionate cities projects were designed to build the capacity of communities to support health decisions through the provision of information by public engagement with issues around illness and death [38–41]. Community capacity public health strategies position consumers and community members as either *receptive* to educational and health promoting strategies; *active participants* in their own learning and that of others; or as *initiators* of health promoting strategies in their local communities.

Wide dissemination of the book *Dying to Know* [42] by palliative care staff in Australia is an example of a *receptive* public health strategy, where the provision of information in an attractive largely pictorial book format met a number of information needs. Images and text juxtapose to match the information-processing requirements of different people with varying levels of health literacy. Facts, figures, poetry and instruction sit alongside compelling images and address different styles and levels of learning. Yet, despite widespread distribution by the publisher, and enthusiastic uptake by community workers, health promotion officers, nurse navigators, general practitioners and palliative care staff, little is known about the impact of the book on health decisions or the role it has played in communication around death and dying.

A Canadian study [41] showed it is possible to design research studies in these areas to demonstrate an effect by looking at concrete measures. A trade-show designed to raise the profile of palliative care in the community was used as an opportunity to find out more about the level of knowledge of dying among show attendees. As they arrived attendees were surveyed on key issues related to palliative care. Despite the biased study sample, which had a higher level of education than the general community, there was confusion between treatment for pain and euthanasia. Unfortunately however, the researchers did not assess the impact of the trade-show on changing knowledge with a follow-up survey.

Another Australian initiative based on research from the World Cafe [43], the *Café to Go* project enables local people to become *active participants* in their own learning about loss, grief, illness and death [39]. Local people, including health providers, educators, volunteers, and service providers (e.g. bus drivers, hairdressers, shopkeepers) meet in a local café to engage in a facilitated process that provides an opportunity to reflect on important questions. During a *Café to Go* evening each participant moves around the different tables, meets other people and discusses provocative questions related to chronic illness, loss, grief and death, such as: How do you cope with the death of a child?" and "What is your biggest fear related to cancer?" [39,40]. Unfortunately, while we know some people reported these experiences as helpful to them, and there were suggestions of increased involvement in palliative care activities, it is not possible to draw firmer conclusions about their effectiveness because of the limited evaluation. Other examples of interactive health promoting strategies include the use of drama productions and hypothetical panels to examine issues not usually discussed. Drama has been used to present case studies of issues related to adult predictive genetic testing; the researchers argued that the play had considerably broader reach than the usual surveys for a similar cost [44]. In Australia, a play *Four Funerals in a Day* toured urban and rural regions to raise community awareness of the issues around advance care planning, palliative care, death and bereavement. The long-term impact of the play was evaluated with regard to local feedback, but not in terms of changes to community communication patterns.

Likewise, there is some evidence that local communities and cancer/palliative care services are requesting support to become *initiators* of their own capacity-building strategies. Emerging research reveals a list of activities that demonstrate health promotion and community engagement in a number of countries including the UK, India, and Malaya [45–48].

However, there is an urgent need for further research that not only identifies local uptake and short-term gains but also addresses broader questions of outcomes. Information strategies that aim to increase the capacity of the community to support health decisions and self-care are often presumed self evident, but they should be considered in terms of investigating what works best and how frequently activities are needed over a particular timeframe to achieve the desired outcomes. Evidence is required about the feasibility of costs and effort and the adaptations needed to increase local acceptability. Likewise, systematic exploration of the transferability of local, contextual and situational findings to other settings, populations and countries, is urgent. As more resources are diverted to these types of activities it becomes increasingly important to shape research questions that address the issues of outcomes and effectiveness.

Decision support processes across the cancer journey

Decision processes are important components of the framework that supports the cancer journey. They comprise those processes designed to facilitate information-sharing and shared decisions across the cancer journey and create the 'decision environment' or culture in which decisions occur, rather than focus on specific treatments and preventive or screening decisions. This means that some decision processes incorporate a series of sequential decisions and allow for the possibility to review decisions. Over the past decade three innovative decision processes that have been established are patient portals, patient navigators (or care coordinators), and advance care planning (ACP).

Patient portals

Access to appropriate information is a key support mechanism for patients diagnosed with cancer. Most cancer patients want as much information as possible and wish to be involved in treatment decisions, yet we know that general information about health conditions can increase anxiety due to the overwhelming amount of information, some of which is not relevant to the circumstances [49]. A key direction for e-health is the individual electronic medical record (EMR); many countries have extended the use of the Internet to allow patients access to specific personal health information via a secure patient portal.

Research in the area of patient portals and electronic health records through the Internet is increasing. Evidence shows that the value of EMR lies in its accessibility via web-based platforms so that

individual centralized patient information can be accessed by health professionals, regardless of location [50]. Many EMRs have functionality that allows patient access to personal health information, with some systems even allowing patients to alter their records and communicate with their health care provider [52].

We know that not everyone is comfortable using the Internet as a health resource and not everyone wants access to their patient record, but findings show that those that do are enthusiastic about it [52,53]. Lack of access, unfamiliarity with technology, distrust of content and fears of being overwhelmed, confused or frightened by web-based information, are cited as common barriers, particularly in older age groups [54,55]. Computer ownership and Internet access are lower among rural dwellers, people aged 55 years or more, lower income earners, unemployed, and/or those with lower education levels [56,57]. There can also be a low level of engagement among health providers who view health records as communication tools to share with other professionals not patients [52], however practical experience has changed negative provider attitudes [58].

Despite these barriers, patient portals provide an effective means of patient access [59–61] consistent with the increasing preference among patients for personalized information based on their own medical records. Further research into the possibilities of e-health and patient portals as key communication strategies are essential.

Patient navigators and care coordinators

Another new area of practice is the provision of trained staff to help guide individual patients by facilitating the transfer of information along the cancer journey. These roles have a variety of names including patient navigators, contact nurses, cancer care co-ordinators or case managers. They also appear in other guises, such as breast or prostate care nurses [62]. The role usually involves assisting patients and families to navigate health-care systems, coordinating appointments, streamlining investigations, providing explanations of procedures and advocating for patients when appropriate. Provision of information about service options and clinical trials are important aspects of the role in some settings [63].

An issue that arises in examining the research evidence is the lack of clear consensus about the scope of these roles or the tools used to evaluate their effectiveness. Indeed, it has been argued that flexibility in the role is inherent to its value [64], but this creates difficulties for researchers keen to codify patterns, identify measurement tools and test agreed outcomes. For example, in US studies, the role has been confined to improving rates of cancer screening, but in other jurisdictions the role is used from diagnosis throughout the cancer journey. The limited studies available use a range of evaluation measures such as reduced time to diagnosis [65,66], compliance with screening recommendations [67], reduction in broken appointments [68] and alleviation of distress or anxiety [66]. Differences in the scope and range of outcomes across studies suggest little agreement about the intended impact of the role at this stage. It also makes comparison of different models difficult, even if similar goals are articulated.

For example, although a Cochrane systematic review of specialist breast care nurses identified five relevant randomised controlled trials involving over 1000 women, there was limited evidence to support the role because of the large heterogeneity across the different studies [69]. The studies varied in a number of ways: the roles undertaken by the nurses were different; there was a wide number and diversity of outcome measures; and there were differences in how the study populations or data were reported in terms of age or stage of breast cancer. The review authors concluded that there was sufficient evidence from three trials to show that breast care nurses appeared to have some positive effect on quality of life in the short-term, but this was difficult to distinguish from the impact of the multi-disciplinary care team generally.

A mixed-method evaluation study of a nurse-led intervention in cancer care also suggests that such a role has potentially positive effects on quality of life. The study followed more than 700 cancer patients over 12 months and found that it was possible to reduce unmet supportive care needs using direct care from nurse-led clinical case management that included coaching for symptom management, counselling and support to navigate the system [70].

In the context of screening, the patient navigator role has clear goals, and randomised controlled trials in the USA have shown patient navigators improve colorectal cancer [67,68,71] and breast cancer [72] screening rates among disadvantaged groups. Another trial found patient navigators reduced the time to appointment for people recommended to genetic cancer counselling [65]. Generally however, there is emerging evidence that the use of specialised oncology follow-up after cancer treatment [73,74] is costly and unjustified. A qualitative synthesis of published literature on cancer patient navigation [75] identified that further research is needed to evaluate their efficacy and cost-effectiveness in improving cancer care.

Planning for End of Life care - Advance Care Planning

Lack of preparedness for death can lead to considerable distress, guilt and regret for relatives, particularly if urgent decisions are needed [76]. Medical emergencies can happen to anyone and deathbed discussions often cause discord and complicated grief in families. As needs change over time, decisions on medical treatments, preferred decision-maker or site of death may also change. Advance Care Planning (ACP) is a process designed to address medical needs and answer questions such as "Would this person want me to continue to treat them aggressively when there is clear evidence that they are dying?" Increasingly it is considered a public health intervention. Internationally, ACP describes a number of single or multi-component processes such as Advanced Directives (ADs) or Living Wills, a durable power of attorney and a Statement of Choices or Values Statement [77]. ACP enables people to anticipate decisions and express their preferences for future care in the event that they are unable to speak for themselves, including the extent of life sustaining measures they desire, preferred site of death and other personal or religious preferences. As a person ages, Advance Care Plans can be re-visited to ascertain whether circumstances have altered and whether the trusted decision-maker remains the most appropriate person for that role [78].

Early research by Hammes and Rooney [79] demonstrated that ACP needs to start in the community. Rather than waiting until a person is seriously ill, when discussions are often shaped by treatment options such as the use of resuscitation, early conversations enable broader discussion on the values and hopes of a person including their choice of a trusted decision-maker, leaving more specific medical decisions for later in the illness trajectory [80]. Further research has explored how these conversations occur over time, examined changes in meaning [81] and the projections of substitute decision-makers [82].

A range of information interventions to promote ACP discussion have been investigated, including structured interviews, meetings, use of videotapes, booklets or written ADs [83] or decision aids [84] to assist people and their decision-makers when discussing end-of-life decisions. Appointing a durable power of attorney is more efficacious than writing an advance directive as it is not possible to pre-empt all scenarios that may occur in a crisis [85]. The complexity of legal information that informs ACP can be detrimental to informed health decisions, particularly with socially vulnerable people, who may be less likely to have an ACP [86–88] and more likely to have their Plan disregarded because it is too narrow and legalistic [83]. ACP completions are more common when a one-to-one conversation has occurred and significantly higher when repeated targeted conversations occur [89]. Substitute decision-makers are more likely to accurately predict patient preferences for end of life care when communication between them is actively promoted [90].

Planning ahead for difficult decisions requires effective and ethical communication all along the cancer journey [91,92]. Although a systematic review [93] examining prognostic and end of-life communication with adult patients in the advanced stages of a life-limiting illness with their caregivers found individual differences, high levels of need for information was common at all stages across the illness trajectory. The desired information included details about the illness itself, likely future symptoms and their management, and anticipated life expectancy. This is consistent with findings from our own ongoing research.

These are complex interventions, and reviews demonstrate that health professionals need training in advanced communication skills, and knowledge of legal, professional and institutional policies and regulations associated with ACP practice [94]. Targeted research is needed for strategies to support staff communication, monitor ACP discussions, audit documentation and ensure processes are in place to implement the decisions that people have planned in advance [95].

Conclusion

In developed countries there is a clear trend towards public health policies and strategies directed at creating informed consumers and supporting a partnership approach to health decision-making. This direction is consistent with the research literature, which time and again reveals that consumers, families and communities require better quality information that is targeted and timely to support the difficult and complex decisions that confront them across the cancer journey. The paradigm shift towards self-determination in health decisions is supported by a number of innovative mechanisms and processes. The challenge for researchers is to design flexible and responsive research strategies that accommodate change, examine different types of evidence for complex interventions and measure a range of outcomes at the patient, provider and system levels.

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