

Defining information need in health – assimilating complex theories derived from information science

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Abstract

Background Key policy drivers worldwide include optimizing patients' roles in managing their care; focusing services around patients' needs and preferences; and providing information to support patients' contributions and choices. The term *information need* penetrates many policy documents. Information need is espoused as the foundation from which to develop patient-centred or patient-led services. Yet there is no clear definition as to what the term means or how patients' information needs inform and shape information provision and patient care.

Theoretical synthesis The assimilation of complex theories originating from information science has much to offer considerations of patient information need within the context of health care. Health-related research often focuses on the content of information patients prefer, not why they need information. This paper extends and applies knowledge of information behaviour to considerations of information need in health, exposing a working definition for patient information need that reiterates the importance of considering the patient's goals and understanding the patient's context/situation. A patient information need is defined as '*recognition that their knowledge is inadequate to satisfy a goal, within the context/situation that they find themselves at a specific point in the time*'. This typifies the key concepts of national/international health policy, the centrality and importance of the patient.

Conclusions The proposed definition of patient information need provides a conceptual framework to guide health-care practitioners on what to consider and why when meeting the information needs of patients in practice. This creates a solid foundation from which to inform future research.

Introduction

Globally health policies identify the need to develop patient-centred and patient-led services, firmly placing the patient at the centre of service design and delivery, an approach

widely advocated by the World Health Organisation.¹ Governments within the European Community share a consensus view that the future of socialized health care is being responsive to person-centred defined needs.²⁻⁴ In UK health policies⁵ in particular National

Service Frameworks for older people, children, specific acute or chronic illness and social care, have been or are being developed with these goals in mind.⁶⁻⁹ Recognizing the need to optimize the role of patients in the management of their care; focusing services around the patient's needs and preferences to facilitate patient choices; and providing the information to help them make those choices are key policy drivers worldwide.^{4,10-12} The term *information need* penetrates many policy documents, espoused as the foundation from which to develop patient-centred or patient-led services, but in health there is no clear definition as to what the term means, or how patient information needs, once identified, inform and shape information provision and patient care.^{3,9,13}

Historically, within health-care *information need* has been used as a primitive term resulting in little definition and understanding of how it behaves, what it is and what it is not. A policy report by the Consumers' Association explored patient information suggesting that information need is often treated as '*self-evident or intuitive*' within the health-care setting.¹⁴ (p. 5) And it is not just within health that have definitions been elusive. In the field of Library and Information Science, where copious research has taken place on user information needs, there lacks common understanding of the term, although explanations demonstrate some shared elements.¹⁵ Theorists from information science such as Wilson,¹⁶ Dervin,¹⁷ and Savolainen¹⁸ studying user information behaviour have considered the purpose of information to the individual in their environment and information seeking alongside how information is used to generate a deeper understanding of the characteristics that influence and/or activate information needs. This body of work has much to offer health professionals and researchers when understanding patient information needs within health.¹⁹

The purpose of this paper was threefold: to identify a working definition for the term *information need* that is both applicable and useful within the health- and social-care arena; to expose the key concepts surrounding information need, the factors that influence how a need

is perceived, represented and portrayed; and to highlight the potential contribution that models of information behaviour/need can make to health and health research.

Information and knowledge

It is important at the outset to offer clarification between the key concepts of information and knowledge that form the basis of many postulations regarding information need. Depending upon the originating theory or discipline boundaries between the two concepts can be blurred.^{20,21} Differentiation between concept characteristics propose that: information, by being told, is acquired (external to the individual); whereas knowledge is information that has been given meaning and understanding through thinking (internal to the individual).^{22,23} In addition, without taking on new information new knowledge can be acquired;²¹ knowledge itself can change, as soon as new information is discovered, causing people to change their thinking; using dated knowledge as information.²⁴

What is an information need?

Within the field of information science information needs are thought to arise from basic human needs that have cognitive, physiological and psychological/emotional qualities.¹⁶ Many theorists agree that information needs emerge because of an underlying '*dissatisfaction with their existing situation*'.¹⁵ (p. 297) A deficiency in a person's knowledge,²⁵ a '*gap*' in life's experience,¹⁷ or a state of uncertainty²⁶⁻²⁸ defined and recognized by the individual, motivating them to seek answers and form questions to find a solution for a particular problem.

Within the context of health, information need is also perceived to represent a gap or knowledge deficit that could be rectified by information and/or education.^{29,30} A simplistic explication offered by Timmins specified an information need '*as what the client needs to know*'.³⁰ (p. 379) However, the phrasing of *what the client needs to know* is in itself ambiguous,

suggesting that client information needs may not always be determined by the client/individual, but biased by professionals who consider certain information to be appropriate,^{30–33} reflecting practice within some health-care settings.^{15,29,34} Timmins acknowledges this tension and highlights that the client's own expressed needs are central to this particular definition.³⁰

Health-care education has developed over time based on, amongst many others, theories of adult learning³⁵ and self-care³⁶ promoting the need to identify the patient's education needs. This had led to concepts such as learning/education needs and information need being used synonymously to explore what information individuals want.²⁹ Confusion propagates as definitions suggest information can be perceived as an act of informing which occurs when education takes place, and information can in itself be educational.³⁷ Differentiating between education and information need is necessary. Although both imply a knowledge deficit, education need refers to a cognitive knowledge deficit, measured objectively (often by someone other than the individual)³⁰ compared with information need, a subjective cognitive and/or affective knowledge deficit,¹⁴ recognized by the individual.^{16,17,21,38} Both could be managed using information to satisfy a need,¹⁴ to improve knowledge and improve health outcomes, but education aims to modify health behaviour.^{30,33}

Case, after reviewing perspectives in information science, proposed a more comprehensive yet practical working definition that '*information need is a recognition that your knowledge is inadequate to satisfy a goal that you have.*'²¹ (p. 5) This definition introduces the dimension of purpose³⁹ acknowledging that the knowledge deficit is recognized because of an underlying goal that cannot be reached without it.^{40–42} Case's definition of information need when applied to the field of health, appears both pertinent and transferable, placing the patient at the centre, their recognition of a knowledge deficit being the focus, but linking lack of knowledge with the need to realize a specific goal.²¹ However, to enhance theoretical lucidity it would seem appropriate to scrutinize other key

concepts and dimensions that both influence and initiate the need for information before such a definition can be accepted.

Conceptual influences of information need

Given that '*information needs do not arise in a vacuum but rather owe their existence to some history, purpose and influence*'²¹ (p. 226) it is not surprising that the context and situation of the individual are key dimensions that must be considered in relation to understanding information need.⁴³ As in health care, the holistic view of an individual based on physical, psychological and social dimensions albeit idealistic, the drive to view the real world of the user of information permeates Information Science. Part of this originates from the Sense-Making work of Dervin^{38,44,45} who advocates that the study of a person's reality and *gaps* in that reality for which people need information has to take place in context. Key concepts that influence and/or activate information needs can be grouped (for the purpose of this discussion) under four key theoretical dimensions:

1. Goals/purpose
2. Context
3. Situation
4. Time

Goals/purpose of information need

There is strong support for the opinion that information needs emerge because of an underlying purpose, to meet a goal or activity.^{21,39,42,46,47} Wilson identified that one of the problems with studies of users of information is the failure to ask the user why they decided to seek information and the purpose it will serve.⁴⁸ Allen suggests that '*information needs happen to individuals embedded in a range of social situations*'⁴⁶ (p. 88), thus a person's information need is situated in the context of some other purpose or task. He proposed a *person-in-context* approach, to understanding information needs, useful within the field of health when attempting to understand the different motivations (*tasks*)

behind the goals (*embedded tasks*) in which information needs arise. Studies identify tasks/goals such as coping with a health-threatening situation, having to participate or be involved in making a medical decision, or the need for behaviour change to prevent further problems.^{30,42,49,50} In reality, a patient could be faced with managing multiple goals simultaneously.^{30,42}

A frequently cited study within health is that by Coulter *et al.*³¹ who derived a broad generic framework for patient information needs in terms of the purposes for which information is used (Box 1).

Although the framework is useful, it provides little insight as to whether tasks are: prioritized, temporal or continuous, related to a specific event, situation or context and relevant to individuals and/or groups of patients.

Evidence suggests that goals are hierarchical and the priority placed on goals and in turn information needs is directly dependent upon the context and situation in which an individual is located.^{18,30,40,45,46} For example, following an acute event cardiac patients have been observed to prioritize information that is pertinent to survival (*task*) such as symptom management, cardiac anatomy and physiology, medications and physical activity (*embedded tasks*).^{29,51,52} Studies of cancer patients indicate that developing an understanding of the illness (to facilitate coping and reduce uncertainty), specific information about the possibility of a cure,

prognosis, spread of disease, treatment, side effects and medication were particularly important when first diagnosed.^{53–57} Embedded tasks, for patients relating to broader lifestyle goals such as exercising, diet control or psychosocial issues are important long-term but less of a priority at the time of an acute event or life-threatening/life-changing diagnosis.^{29,51,52,54} It becomes impossible therefore to consider goals and information needs without understanding the context, time and situation in which they transpire.

Information need in context

The importance of studying information need in context is reinforced by theorists and researchers.^{17,18,40,43,58–62} Many information behaviour models portray the process of information seeking within Information Science²¹ but one in particular, Wilson's 1996 Model^{40,63} provides a comprehensive yet simplistic overview of the contextual factors that influence an information need.⁶⁴ Wilson separates the occurrence of need with what he terms '*activating mechanisms*' and '*intervening variables*'⁴⁰ (p. 257) for information seeking. Key contextual concepts drawn from the Wilson Model include the influence of psychological, stress, self-efficacy, demographic, role-related and environmental factors. He argues the barriers that impede the search for information arise in the same context in which the information needs occur.⁴⁰

Psychological

When generating information needs cognitive, physiological and affective, psychological/emotional variables can interplay.^{21,40,44,64} These include individual's existing knowledge, their outlook on life, stereotypes, prejudices, preferences, self-perception, emotions, interests, memories, intuitions, attitudes, feelings, experiences, motivations and personality, which influence how information needs are conceived and represented.^{16,17,27,61,65,66} Disease specific variables or illness/treatment-related symptoms, such as cognitive decline in dementia patients or chronic kidney disease and dialysis treatment,

Box 1 Framework for patient information needs³¹ (p. 319)

- Understand what is wrong
- Gain a realistic idea of prognosis
- Make the most of consultations
- Understand the processes and likely outcomes of possible tests and treatments
- Assist in self-care
- Learn about available services and sources of help
- Provide reassurance and help to cope
- Help others understand
- Legitimize seeking help and their concerns
- Learn how to prevent further illness
- Identify further information and self-help groups
- Identify the 'best' health-care providers

are likely to impact upon an individual's ability to both recognize and verbalize an information need, and organize information.^{19,67} Psychological states of anxiety, depression and feelings of control may affect information needs.⁶¹ An individual could experience cognitive uncertainty manifesting as anxiety²⁷ resulting from their judgment of the knowledge required to overcome challenges or problems.⁶⁸ In addition, they may experience uncertainty related to feelings of insecurity and pessimism.^{28,69} A person who perceives that they have sufficient knowledge to overcome a problem or make a decision will not identify an information need.¹⁶

Stress and coping

Context can be perceived on a cognitive level. The more an individual's central life goals, for which they may require information to achieve, are threatened by illness the more stress the individual experiences influencing their coping abilities.⁷⁰ Two recent systematic reviews of patient information needs in health-care settings found that managing stress and coping were the underlying focus/goals of information needs within the majority of studies.^{30,55} There is particular reference to Lazerus and Folkman's work on stress and coping.^{71,72} When faced with a stressful encounter an individual first appraises the situation with respect to what is at stake, what coping resources are required, and what options are available.⁷² Making sense of what is happening, identifying and satisfying information needs plays an important part in helping patients cope with the demands of their illness.^{49,50,55,73,74}

Behavioural responses to stress and coping influence how an individual perceives the depth of a gap in knowledge and the need for information.⁷⁵ Some may use avoidance if they have information overload or the 'gap seems too big'⁷⁶ (p. 6), for example at diagnosis, generating too many information needs to satisfy in the time available.^{32,50,53,57} Having too much or too little information can increase the fear of uncertainty and anxiety.²¹ Misunderstanding a problem may result in being unable to articulate or recognize the need for information, or it may simply not be

personally relevant.^{77,78} Indeed, individuals have been found to exhibit transient coping styles depending upon the personal significance of an information need to their current situation; major life event, specific point in the disease trajectory, age, or as a result of a physical factor (such as tiredness).^{79,80}

Self-efficacy, beliefs and control

Similar interrelated concepts to consider alongside motivation and personality are self-efficacy and locus of control with respect to information behaviour, the recognition and generation of information needs.^{18,40} Self-efficacy beliefs determine how people think, motivate themselves and behave.^{81,82} Perceived self-efficacy is defined as an individual's self-belief in their own capabilities to be able to influence events that affect their lives.⁸¹ Individuals with strong self-efficacy set higher goals, verbalize information needs and demonstrate greater commitment and motivation to achieve them. Those who believe they have the coping skills to control threats or challenges are less vulnerable to anxiety, stress and depression.⁸¹ Lack of self-belief and feeling a lack of control over the situation, disease, treatment and decisions could inhibit the recognition of an information need.⁸⁰

Sense of coherence⁸³ theory describes the ability to create meaning or sense of stressors in the presence of illness. When faced with a stressor an individual with a strong sense of coherence will believe they understand the challenge ahead, be motivated and have the available resources to cope.^{70,83} Savolainen suggests that for a person to have mastery of life skills (an ability to keep things in order), they must have a sense of coherence.¹⁸ An individual's health beliefs; their perceived severity and susceptibility to a health outcome and its consequences are closely associated with the motivation to act.^{84,85} Apprehension about their condition, particularly if terminally ill, can generate a conflict between wanting to know and fearing bad news which impacts upon the level of information they feel they need.⁵⁷ People may defer or ignore emerging information needs and subsequently not seek information if they feel

unable to influence a situation, such as when being diagnosed with a chronic condition.^{19,80}

Demographic

Demographic variables such as age, gender, social and economic status, level of education, ethnicity, health status, diagnosis and stage of disease have all been posited as factors or intervening variables that influence information needs.^{21,40,53,55,56,78,86} For example, younger patients have been shown to need more information than older patients, maybe a result of different coping styles or life expectancy.^{57,61} The non-participatory role adopted by some men and older patients in the management of their illness has also been seen to be a factor in their reduced need for information.³² Some women have been found to seek more information than men, in particular females with higher incomes.^{55,56} Income and education have also been shown to be positively associated with the need for high levels of information.^{55,56} Conversely other studies suggest no relationship between gender, education level, time since diagnosis and stage of illness and information need.^{54,61} A lack of consensus exists as to whether particular characteristics with respect to information need, can be consistently associated with a specific demographic group^{21,87} signifying the need for further synthesis of existing research.

Role-related and environmental

Information needs are considered to be personal, idiosyncratic and shaped by personal circumstances and values.²¹ Individuals can play many social roles within the family, in society, related to their occupation and as a patient. Certain roles indicate specific information needs and the needs of individuals within the same groups are dependent upon changes in the environment.⁶⁴ Work-related or occupational roles, the type of work, the social norms guiding the work, values regulations and limitations, an individual's position, level of responsibility, experience and knowledge will shape and stimulate different information needs.^{64,88,89} Social and occupational networks influence the way in

which information is perceived and used.^{88,90} In any setting including health-care environments the local core values, delivery of care, provision of information, norms, constraints and opportunities need to be considered to understand how information needs are formed and influenced by such contextual factors.^{33,62,78,91,92}

Situation-related information need

A term closely related to context is situation, usually used with a narrower meaning²¹ defined as particular set of circumstances in which people find themselves that creates an awareness of an information need.^{61,90,93} Dervin's Sense-Making was developed with the ultimate aim of finding out what users '*really think, feel, want and dream*,'⁹⁴ (p. 39) understanding the intrinsic connection between how an individual views and constructs sense from a situation.¹⁷ Situations can be events, critical incidents, encounters, experiences or activities that occur at a moment in time located within the wider environmental and personal context of the individual. Information is interpreted with respect to the past, present and future, drawing on previous experiences of situations and existing knowledge, comparing this with the current situation and the goals for the future.⁴⁵ Individual interpretations are '*influenced not directed or dictated by the environment*.'⁴³ (p. 31) An individual may be an expert in some situations (work related) but a novice in others (health problems).⁹⁰

Since 2000 an increase in publications, particularly in the field of cancer suggests a renewed and growing interest in patient information need likely to be instigated by policy directives.⁵⁵ Given that one of the first information needs questionnaires⁹⁵ was developed within the field of cancer care, over 30 years ago the prevalence of cancer studies exploring information need is not surprising.^{32,49,50,53–56,61,95–100} Research has since followed in other health fields such as asthma, polycystic ovarian disease, multiple sclerosis, lung disease, cardiac rehabilitation chronic kidney disease and spinal injury.^{29,30,34,52,79,101–106}

Health studies predominantly identify that situations arise as a reaction to a stimulus such as life changes, perceived threats or life-threatening and incapacitating illness³⁰ and/or stress and anxiety.^{49–51} Threatening situations could be one of several reasons that stimulate a need for information.⁴² Indeed a situation could be as simple as a clinic appointment, meeting other patients, or discharge from hospital, experiencing a symptom, a decision regarding treatment options, rehabilitation, or a different stage of a progressive illness.^{30,52–54,56,57,79,92} In response to changing situations, events and experiences information needs and preferences for information inevitably change.^{19,53,79,92,96}

Information needs and time

Information needs are temporal changing over time along the disease continuum related to a series of challenges, critical and/or social events.^{17,21,107} Attfield *et al.* identified numerous information needs experienced over a short-time period, within the context of a clinic consultation.⁹² Similarly Godbold found that individuals have ‘*more than one gap at a time*’ and although some information needs were satisfied (during the consultation) others remained as ‘*ongoing gaps*’.⁷⁶ (p. 12) Information needs, can be deferred, like goals placed on one side whilst a person focuses on those that are at the time more salient or personally significant.⁸⁰ One gap might lead to the discovery of other gaps, which need to be navigated first or ignored till a later date.²¹ This is observed in patient studies where information preferences and priorities highlight which gap they consider relevant to their current situation at that point in time influenced by both personal and environmental factors.^{13,51,53,79} Julien and Michels identified, by observing one individual in their every day life, information needs were influenced by time pressures and coded ‘crisis’ – needed today, ‘short term’ – within a few days, ‘long-term’ – within a few weeks, ‘undetermined’ – no set time.⁹³ (p. 552) Often lack of time prevents individuals meeting their information needs even when they are highly motivated to do so.¹⁰⁸

Patients across studies, whether experiencing an acute or chronic illness have been shown to fluctuate between the desire for more and the avoidance of information at different times during their illness, or disease trajectory.^{29,32,50,77,79,80} For some patients, when first diagnosed with an illness, too much information can be distressing and hard to comprehend, whilst other patients prefer limiting the amount of information to match their personal coping style.^{32,53,57,79} By contrast some patients need a constant amount of information, rather than information needs decreasing as the familiarity with and knowledge of the disease/illness or event increases over time, different needs continually emerge.^{51,52,61,79}

Information needs are individual and subjective; contextual personal characteristics influence the choice, hierarchy and salience of an information need,^{61,64,68,79} as does an individual’s perception and interpretation of the situation and environment in which they find themselves⁴³ at a specific moment in time.¹⁷ No two interpretations or responses will be the same, although evidence suggests that patients, both within and across different disease groups, can have similar types of information need that correspond to a point in time/event along a disease pathway.^{19,57,79,92} Diagnosis specific information needs or information needs occurring within an acute event are considerably different to those emerging over the long-term.^{13,51,52,79,80} Indeed where information surrounding survival may be paramount to some patients experiencing an acute ischaemic attack or chronic life-threatening illnesses such as diabetes, chronic kidney disease or AIDS;^{51,52,106} information needs long-term can involve knowledge of symptoms, treatment/medication regimes and restrictions to achieve an acceptable and balanced quality of life.^{26,29,34,51–57,60,79}

Constructing a clearer definition of information need in health

Presented at the outset of this paper was a definition of information need, favouring the notions of Case, that ‘*information need is a*

*recognition that your knowledge is inadequate to satisfy a goal that you have.*²¹ (p. 5) This definition, grounded in information science, incorporates the premise that information needs emerge due to an underlying purpose, to meet a goal or activity.^{39,40,42,46,47} This builds on and brings alive the perception that an information need is a gap in knowledge^{17,29} by adding a deeper dimension that is both meaningful and pertinent to an individual patient.

Acknowledging the dimension of purpose, when exploring and understanding patient health information needs would appear fundamental, particularly for clinicians who equipped with the knowledge of *'why people need the information, the question of what should be much more transparent.'*¹⁴ (p. 18) Indeed, applying such a definition in practice overcomes the ambiguity of the phrase *'what a client needs to know'* and prevents health-care professionals determining the information needs of a patient based on goals which they rather than the patient consider important.³⁰⁻³³

It is known that personal characteristics influence the choice, hierarchy and strength of an information need.⁶⁴ The salience or personal significance of specific information to an individual is determined by their risk/reward assessment as to whether it is beneficial or harmful to know.⁸⁰ For example, patients' diagnosed with a chronic disease may decide that understanding the disease is paramount or secondary to financial stability or sustaining employment.⁷⁹ Some information needs will be more relevant and salient at different stages in the sense-making process.¹⁰⁹ The timing and situation in which a patient is located, their personality, psychological state, alongside the stage of the illness (acute or chronic) will all contribute to the decisions of information need significance.⁸⁰ Self-motivation can be seen to increase when an information need is personal, identified internally rather than imposed externally.¹¹⁰ Given the strong evidence that indicates the personal relevance of patient information need much of the health research to date asks patients what information they prefer to receive from a health-care professional overlooking the purpose for

which the information is required and the context and situation in which the need arises.^{31,79}

Although the definition posited by Case²¹ provides a useful foundation for a working definition of patient information need, further modification is required to encompass and fully recognize the interplay of all four key dimensions: context, situation and time alongside purpose/goals (see Box 2).

The pivotal role of the health-care practitioner is to help the patient articulate and refine their information needs, then provide the relevant information to satisfy the need or gap in knowledge. A comprehensive and crucial understanding of what, why and when information needs arise for the individual patient, can only be achieved by exploring all the key dimensions highlighted in the modified patient information need definition, with the individual patient (Box 2).

Identifying and meeting the information needs of patients is considered pivotal to developing patient-led services. Indeed, the contextual and purpose-based definition of information need proposed here epitomizes the key concepts of national and international health policy, being the centrality and importance of the patient.^{10,12} Alongside it provides a clear conceptual framework that will guide health-care practitioners and information professionals on why and what to consider when meeting the information needs of patients in practice.

The format and source of information provided is also important. Indeed patients have demonstrated preferences for face to face verbal information provision, providing the opportunity to ask questions,^{32,52,53,79,80} preferably by the medical doctor^{29,79,80} reinforced by the nurse, supported by written information and/or videos.^{32,52,55,80,99-103} To meet information needs of the individual patient the content of

Box 2 Definition of patient information need [modified from Case²¹ (p. 5)]

'Information need is a recognition that your knowledge is inadequate to satisfy a goal that you have, within the context/situation that you find yourself at a specific point in the time'

information provided needs to focus on the patient not professional agenda.^{15,33,42}

When information provision matches the information needs of patients the outcomes are generally reported positively.⁶⁰ Indeed giving patients information that they want, increasing their knowledge and meeting their information needs has been shown to: improve functional adjustment, reduce stress and facilitate coping;^{30,55,61} improve well-being and personal control;^{42,103} create more knowledgeable and competent patients;^{42,60} increased self-management, self-care and compliance with treatment;^{96,111} and reduce dependency on health services.¹⁰³

Conclusion and recommendations

The assimilation of complex theories originating from other scientific domains, models of information behaviour/need have much to offer patient information need within the context of health.¹⁹ This work reinforces, extends and applies expertise and knowledge of information users^{17,21,40} with research measuring information need in health to expose a working definition for patient information need, applicable to health-care practice. The definition of patient information need provides a platform upon which to clarify the meaning of national policy, to inform and guide future research and facilitate information provision based on the needs and goals set by the patient, relevant to their individual situation and context. As such two clear recommendations emerge:

1. The working definition of *information need* be integrated throughout policy documents and future research within the wider field of health to generate a clearer understanding of what the term means and the dimensions surrounding the concept
2. Health-care professionals are educated regarding the fundamental theories underpinning the initiation and influences on patient information need, to develop a deeper understanding that in turn will enhance information provision.

Conflict of interest

None.

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