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Addressing the challenges of patient-centred design

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REVIEW

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Abstract

Patient-centred design is a relatively new term, but a long standing concept in clinical practice. This discussion looks at patient-centred design and explores the relationships of patient-centred design to universal design, user-centred design and the newer human-centred design. It also explores why interdisciplinary approaches are needed for patient-centred design and how interdisciplinary collaboration works to address the challenges of patient-centred design.

Successful patient-centred solutions can grow from collaborations which include shared visions, understanding of both the nature and degree of variation in the patient, materials, and the designed solution, clear regular communication among all parties with careful definition of terms, and respect for the inherent cultures of all disciplines involved.

Introduction

Patient-centred design is a relatively new term which is appearing with increasing frequency in the medical literature. Although it is currently often used as a descriptive noun, it is also an active process similar to but also different from patient-centred care. To be used to its' greatest potential, the process, patient-centred design, requires a moderately detailed level of understanding by both design and medical professionals.

Much like the process of differential diagnosis of a disease in a patient, patient-centred design is a highly complex process. The Oxford English Dictionary Online defines the verb, design, as: "To form a plan or scheme of; to conceive and arrange in the mind; to originate mentally, plan out, contrive." [1] Design, as a process, however, is more than this. Design is an art, and in its' best practice it is an iterative process which assesses needs broadly and proposes a wide variety of potential solutions before selecting a prototype solution which is then tested and revised as needed. Patient-centred design is focused on the patient and the patient's specific needs, but must also consider multiple other factors including everything from the other individuals interacting with the patient to the environment and economics of the patient's situation.

This paper will delineate and discuss the concept, "patient-centred design." It will focus on patient-centredness and the definition of design as a process as well as the variety of end products of design. This exercise also includes a discussion of several specific approaches to design. Finally this paper will suggest how interdisciplinary collaboration works to address the challenges of patient-centred design.

Method

Patient-centred design is a highly complex process. Capturing its essence is difficult as the process requires both a long view, as a generalist, and a near microscopic interest in minute details. This discussion paper explores a wide literature in design, clinical medicine and interdisciplinary research to probe the nature and history of the idea of patient-centred design.

Two articles were identified as starting points for the "patient-centred" and "design" components of "patient-centred design". [2], [3] Patient-centredness in health care is a concept introduced in the late 20th century and recognized as an important component of quality health care. In 2001, the Institute of Medicine (IOM) included it as one of the six key aims of health care, the others being safety, effectiveness, timeliness, efficiency and equity.[2] Elaborating on the term patient-centred, the IOM identifies consumer-centred and individualized as like terms. [2] Patient-centred may be considered as in opposition to the descriptors disease-centred or health care team/health care provider-centred. But, for the greatest efficacy, it must be used in a balance with those concepts.

Design is an active process which has been conceptualized in multiple ways over the past two centuries. Buchanan describes design as an art and as an integration of knowledge, combining theory with practice for new productive purposes. He also identifies design applications in four areas: 1) symbolic and visual communication, 2) material objects, 3) activities and organized services, and 4) complex systems or environments for living, working, playing, and learning. [3] Thus "patient-centred design" can be used in reference to the process of design of products, processes, or environments used by patients. It can also refer to the design process for educational materials for patients or communication tools aimed at health-care consumers.

Patient-centredness

The descriptor, patient-centred, implies an individual with a health care concern or health problem, in the context of a health care process, and as a focus of a health-care provider or team of providers. Patient-centred has been used as an adjective with multiple other terms such as patient-centred care, patient-centred environments, and patient-centred communication. In 1995, the PubMed/Ovid MEDLINE system, introduced the Medical Subject Heading (MeSH) term, "patient-centred care", defined as "design of patient care wherein institutional resources and personnel are organized around patients rather than around specialized departments." [4]

Simply put, patient-centred means putting the patient at the heart of care, education or processes involving patients, or environments and products used by patients. Bethell's expanded definition, in the context of patient-centred care, provides greater insight into the components of patient-centredness:

> Health care that establishes a working partnership with patients and their families to ensure decisions are made that respect and honour patients' wants, needs, and preferences and to ensure that patients have the education and support they need to act as a central resource in their own health and/or the health of their family. [5]

The International Alliance of Patients' Organizations puts forth an even broader discussion of the term patient-centred from the patient's view. [6]

Patient-centred design has roots in the early 20th century. Like may other medical specialties, team members in Physical Medicine and Rehabilitation (PM&R) have been focused on the patient, the patient in the context of their family, and the patient in their environment since the birth of the specialty in the 1920's. PM&R practitioners have particular concern for disabled individuals and include, as a part of their practice, involvement in the patients' welfare.[7] War injuries in the 1940's and poliomyelitis in the 1940's and 1950's brought increased attention to patients' needs for equipment and devices from members of the medical specialty and from the allied health care providers who are integral to the provision of services in the field.

Designed Processes/ Products

Clinicians across medicine started to consider how to put the patients at the heart of processes, products and environments. "Patient-centred design" as a process began to evolve rapidly in the 1990s. Interior design faculty Birdsong and Leibrock proposed patient-centred design to improve the healthcare experience for patients with AIDS. They suggested environmental modifications are made in care settings to 1) reduce isolation and stress, 2) create a home-like atmosphere, 3) promote safety and independence, and 4) enhance the sense of control.[8] The importance of patient-centred design, as a process, has increased as we have moved into the 21st century. It was ensconced as the most important of the four principles of the Proclamation for Change, by the 2007 Nurse Work Environment Innovation Summit (NWEIS). [9] The NWEIS, over 200 nurses and other health care stakeholders, sought to create a set of evidence-based recommendations to transform hospital care; to ultimately enhance patient outcomes.

Patient-centred design processes were used to produce individualized products for patients long before the term itself was coined. Reports of devices designed to assist patients in activities of daily living began to appear in the literature in the 1940's. The scope note for the undated MeSH heading: "self-help devices" provides the definition "Devices, not affixed to the body, designed to help persons having musculoskeletal or neuromuscular disabilities to perform activities involving movement."[10] (All undated subject headings were in use when the MEDLINE® database was launched in 1966). Interest in these customized devices mushroomed through the years. Today the Abledata database, http://www.abledata.com/, begun in a shoebox in the 1980s and moved to the internet in 1996, is a repository of over 36,000 such consumer-centred designs.[11]

During the mid-20th century as self-help devices were designed for patients whose physical and physiological impairments created a loss of function (disability), consideration was also being given to changes needed in the environment to help decrease the handicap those disabilities created in the society. Overcoming mobility restrictions, particularly those related to wheel chair use, dominated this early work, which also illustrates a process of patient-centred design.

Design Standards

Numerous groups began to work on improving access in public buildings and housing for those with mobility impairments. The American Standards Institute, subsequently renamed American National Standards Institute (ANSI), prepared a standard for architectural design, A117.1 in 1961. Goldsmith, with grants from the National Fund for Research into Crippling Diseases (formerly the Polio Research Fund), produced a detailed volume outlining not only specifications for accessibility for those with mobility disabilities, but also arguments both for and against the importance of such environmental changes.[12] The ANSI standards were eventually codified in the United States as the Architectural Barriers Act (ABA) in 1968 and as the Americans with Disabilities Act (ADA) in 1990. The most recent access requirements for a wide range of facilities in the public and private sectors covered by these laws can be found online at http://www.access-board.gov/ada-aba/final.pdf [13] and http://www.access-board.gov/ada-aba/supplement.pdf [14]

Defining Patient Needs

Multiple patient needs, from information to allow individuals to better participate in their own health care decision making, to navigation in and through health care facilities and reimbursement systems, to access to their own support systems, to privacy, confidentiality, and safety in

the medical care system have all been recognized and are among the multitude of appropriate subjects for the patient-centred design process.

While the special needs of the disabled were an early driver of patient-centred design, perspectives on disability have evolved with time. Over the years the World Health Organization (WHO) and the IOM have developed recommended nomenclature for classifying function and disability. Using an international consensus process, WHO published *The International Classification of Functioning, Disability and Health: ICF* in 2001 complete with tools to measure disability by utilizing positive descriptions of human functioning.[15] In 2007 IOM updated their work on disability in the United States.[16] This new report recognizes the need to deal with the impact of disabling conditions beyond mobility limitations, including cognitive impairments and a wider range of physical impairments. These insights are fortunate since, if you stop and think about it, at our best we each have varying degrees of ability and disability and we are all just temporarily able-bodied.

The design methods for self-help devices, now generally designated "assistive technology", have also evolved. The 2008 volume, The Engineering Handbook of Smart Technology for Aging, Disability and Independence is a compendium of information on multiple aspects of assistive technology for persons with a variety of special needs, including chapters on design methods.[17]

Choosing Appropriate Design Processes

Design processes have come to be an integral part of addressing the needs of individuals with differing abilities and by extension they have also come to be important for designing for all patients' needs and wants, too. Moving beyond designing for access, designers have sought ways to accommodate persons with special needs as well as to accommodate a wide range of needs with a single design. From the work of Birdsong and Leibrock [8] in 1990 on, the literature illustrates a developing, broader interest in patient-centred design in many aspects of health care.

Stewart, Brown, Weston, McWhinney, McWilliam and Freeman provide background on the development of the patient-centred model of medical practice and outline six essential components of patient-centredness in clinical situations. They also provide suggestions and insights into teaching the communication tools needed for the model and research methods to evaluate the success of patient-centred processes.[18] The IOM details multiple recommended changes and a redesign of the United States' health care system to better meet patients' needs.[19,20] They identify challenges to the redesign of health care organizations and cite design tools and techniques drawn from industrial engineering for use in the process, ranging from designing for safety to mass customization.[21]

Design processes and designers have an important role to play in patient-centred design. Two well-established design traditions: universal design and user-centred design, have been used to meet the needs of both patients/patient populations and differently-abled individuals. Baecker defines user-centred design (UCD) as design *for* users, participatory design (PD) as design *with* users and patient-centred design as design for/with an individual patient.[22] A new generation of design processes includes extensions of universal design to inclusive design and of user-centred design to human-centred design.

Universal design aims to serve as wide a swath of abilities as possible, and becomes inclusive design when it succeeds in meeting the needs of both impaired and non-impaired individuals.[23] Although it emphasizes breadth of use, it does not ignore the needs of individual users. The Centre for Universal Design defined universal design as: "The design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design." [24] They developed 7 principles of universal design for use in environments, products and processes, shown in Table 1.

As universal design principles are applied across a wide range of needs, the designed environment, product or process satisfies a wider range of individuals. The demand for specialized devices and assistive technologies then declines. The lever door handle, for example, reduces disability for individuals with limited grasping ability related to any number of medical conditions, but also is fully and easily usable by able-bodied individuals. It has become a relatively common fixture in American homes, irrespective of the physical abilities of the occupants. A part of the lever door handle's wider acceptance and success also comes from its aesthetically pleasing lines and visual impact—an emotional aspect of its design.

If universal design does not meet specialized individual needs, increased attention to user-centred design processes is warranted. User-centred design aims to increase the participation of the product/process user in the design process, from the earliest conceptual models to the development and testing of prototypes. Child-sized bathroom fixtures in an elementary school could be considered an example of user-centred design.

Patient-centred design is a highly complex form of user-centred design because the patient, by definition, has a health condition and is in the context of some health-related setting. Wheelchair accessible restroom facilities and designated Handicap Parking spaces near building entrances are examples of patient-centred design in the community. The assistive technologies found in the Abledata database [11] illustrate the wide range of patient-centred problems of function which have been addressed in innovative ways. Yet, tens of thousands of the assistive technologies and self-help devices in the database have been discontinued, presumably because at least in part they were too expensive or were usable for too few people.

In *The Future of Disability in America* the IOM identifies a need for the development of new or improved technologies for assistive devices, a need for improvement of the use of existing technologies, including in medical settings, and a

need for increased awareness and acceptance of assistive technologies for different kinds of disabilities.[25] These needs exist not only for assistive devices but for innovative approaches to problems throughout the patient-health care system interactions, from how health information is shared with the public to even the most basic issue, how health care is defined.

Usability is a particularly important component of user-centred design. In patient-centred design problems, usability applies not only to patients, but to the many other users and stakeholders as well, from hands-on caregivers to insurers and government entities dealing with the cost of health care.

Although the International Organization for Standardization's standard, ISO 13407: Human-Centred Design Processes for Interactive Systems was conceived for use in computer-human situations, the principles and design activities it sets forth are equally applicable to patient-centred design for environments, products and processes. "[Human Centred Design] HCD processes address the consideration of end-users and other stakeholders in the specification, development and operation of a system."[26] The inclusion of all users and stakeholders is an advantage over traditional user-centred design. Table 2 outlines the principles of design as set out in ISO 13407.[26]

Table 3, also derived from ISO 13407, and specifies the activities essential to human-centred design. [26] It is important that the process is iterative for activities 2-5 in Table 3, to achieve usability.

Larsson and Larsson propose what seems a quantum leap in the design process to a value system they call design for well-being (DfW).[27] They highlight the importance of emotion in design and advocate for greater attention to this facet of design. Newell, discussing user-centred design for assistive technologies, predicts an increasing need for attention to the aesthetics of specialized designed objects used to compensate for disabilities.[28] Ilstedt Hjelm considers how to address complex problems when developing artefacts that include interaction with computer technology. She approaches her work with an aim to inform design practice (particularly industrial design) and enhance design solutions with new concepts, advice and examples. She recommends that design knowledge becomes an essential element in research and endorses cooperation between practitioners from the social and technical sciences, the humanities and design.[29] The DfW terminology and approach sounds as if it could become the next iteration of patient-centred design.

Method: Implementing a Patient-Centred Design Process

Designers bring a concern for the visual impact of whatever design solution they are considering. Fisher, discussing the evolution of design as a discipline notes that, although schooled similarly today, the culture and temperament of designers may vary. Architecture is rooted in French rationalism and German idealism and has tended to produce studio-based individual practitioners. Industrial design, on the other hand, is more rooted in empiricism and the Arts and Crafts movement where the designer worked alongside the fabricators and craftspeople.[30] The degree to which designers work in teams is variable but the ability to work in teams becomes crucial if one considers, as Fisher does, that design is an "inherently interdisciplinary, collaborative art form".[30]

Although deciding when to utilize universal design principles and when to follow user-centred or human-centred design methods is a challenge, a greater challenge in solving patient-centred design problems is creating a working interdisciplinary team and executing the needed interdisciplinary research. Effective patient-centred design requires many areas of expertise. Few individuals possess all the necessary skills for the work. Ackerson provides guidance for locating research in developing fields and for approaching the problem of synthesizing knowledge from 2 or more distinct disciplines.[31]

In general, medical practitioners focus more on the details of the physiology/anatomy of the patient and pay less attention to the patient's environment. Designers of health-related products/processes may focus on the points of interface of the patient/client with the environment, while keying less on the physical human variables. A compact team with a shared interest in improvement of the patient's status can meld the professional skills and knowledge bases from both health care and design and use colleague networks to provide supplemental expertise. When a solution, which grows from the knowledge and perspectives of multiple individuals including the patient, is tested, evaluated and revised; the resulting process, product or environment used by patients stands to benefit.

Such teams have great potential but can bring multiple challenges including differing expectations of the possible, divergent endpoints, and a dissimilar sense of urgency. Medical personnel are conditioned to provide a prompt solution to patient problems many times a day. Design professionals work with wider time frames, have been trained in iterative techniques, and often bring greater respect for and awareness of the financial realities of the marketplace. The process is further complicated by the complexity of the human body and behaviour, the sophistication of the tools used in both health care and design, and the ever-expanding range of materials available for product development.

Interdisciplinary teams can successfully use an integrative process to synthesize their separate knowledge bases to solve patient-centred design problems, but the team needs a clearly designated leader and all participants need to exert the effort to stretch their own information funds, keep an open mind, maintain respectful attitudes, and remember their common goal.

Establishing such a team can be a challenge in itself. It is a topic of long standing interest. Brozek and Keys, writing nearly 65 years ago, provide an excellent discussion of requirements for successful interdisciplinary research and

describe the organization and function of the Laboratory of Physiologic Hygiene, University of Minnesota, as a case history. [32]

Future Research

A need exists for research to evaluate the effectiveness of both the end products of patient-centred design and the design processes and teams used to create them. A large portion of the work in this area is completed outside of academia and significant challenges would arise if one proposed systematic prospective studies due to both the proprietary nature of such design work and funding the costs of comparative studies.

An alternative research approach could be taken: select products/processes/environments seeking to fulfil similar patient-centred endpoints from a database such as Abledata or from patent records. Then retrospectively explore the design process and team used to produce the end product and prospectively study the patient acceptance, economic viability, and health outcome success of the end product including emotional/affective impacts on the users.

Conclusion

Patient-centred design offers a process to improve individual and community health over a wide spectrum of problems. Health care and design professionals need to expand their understanding of each other's fields, gain insights into the needs of patients in and outside of health care contexts, and, working together, feel free to dream multiple possible solutions to complex problems. When this happens patient-centred design, as a process, will move forward.

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CONFLICTS OF INTEREST

There are no competing interests to be declared by the authors

Table 1:

The Principles of Universal Design
1) Equitable Use: The design is useful and marketable to people with diverse abilities.
2) Flexibility in Use: The design accommodates a wide range of individual preferences and abilities.
3) Simple and Intuitive Use: Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
4) Perceptible Information: The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
5) Tolerance for Error: The design minimizes hazards and the adverse consequences of accidental or unintended actions.
6) Low Physical Effort: The design can be used efficiently and comfortably and with a minimum of fatigue.
7) Size and Space for Approach and Use: Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user's body size, posture, or mobility.
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Table 2:

Principles of human-centred design
1) The active involvement of users and a clear understanding of user and task
2) An appropriate allocation of function between user and technology requirements
3) Iteration of design solutions
4) Multi-disciplinary design

Table 3:

Human-centred design activities
1) Plan the human-centred design process
2) Understand and specify the context of use
3) Specify the user and organizational requirements
4) Produce designs and prototypes
5) Carry out user-based assessment