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GROWING UP AND MOVING ON - INSIGHTS FROM THE HEALTH CARE PROFESSIONALS AND ADOLESCENTS' PERSPECTIVES ON THE ISSUES AND BARRIERS IN THE TRANSFER OF CARE FROM PAEDIATRICS TO ADULT CARE

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ABSTRACT

The aim of this research is to report the finding from the perspective of the Healthcare Professionals and the adolescents and young adults (AYA's) to identify issues and barriers to a successful transition for adolescents with Juvenile Idiopathic Arthritis (JIA) as they move from Paediatric Healthcare setting to Adult Healthcare.

Healthcare services that fail to adequately meet the needs of young people and their families at this time of considerable change may result in a decline in their health status that can have a negative long-term impact. Through a user-centered research design (UCD) and Universal Design, the needs of all participants and stakeholders will be assessed. This paper applies the most appropriate proposed methods for the development of a solution to mitigate against some of the issues in tangent with the needs and feedback identified during the research process.

Keywords: Juvenile Idiopathic Arthritis(JIA), Transition of care, Early design phases, User centred design, Design practice

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1 INTRODUCTION

This paper aims to provide a broad overview of the issues and barriers encountered by healthcare professional, adolescents and young adults (AYA's) as they transition from paediatric care to adult care with the following long-term condition: Juvenile Idiopathic Arthritis (JIA). From the themes emerging in the data collection process, we aim to extract the pain points in the process, thus allowing for the future development of a design-based intervention. As the data analysis phase is in the early stages and we feel we need to strengthen the perspectives of the AYA's as they are the primary stakeholders in the process. A qualitative study was preformed through a grounded theory approach, contrary to conventional grounded theory studies literature was consulted first as to not reinvent the wheel. We firstly report a brief overview of the transition of care and the issues reported in literature. Semi structured interview with healthcare professional, and a focus group with AYAs were performed for primary data collection, followed by inductive thematic analysis to unearth the common themes from the contrasting perspectives. A design research, user-centered design and Experience-based co-design approach have been assessed to see how these practices may be incorporated to mitigate the issues that arise. Addressing the issues and barriers from a UCD approach involves the users at every step of the process, which may lead to more successful outcomes. The stakeholder groups will have an active investment in how the system runs and works while also having an active involvement in how the solutions are developed. Design research in healthcare can be challenging, deviating from the traditional roles in medical device development, the practice of design in health is now expanding its scope for the future of healthcare practice (Groeneveld et al., 2018). Healthcare systems progressively require innovative ways of supporting patients, such as assisting them to understand the effects of new treatments and how these advances in treatment prolong lifespans (Lopez-Rangel et al., 2008). Shift are occurring in the healthcare systems, rather than being focused on the disease, developments are now more focused on the experiences and the quality of life and their participation in care (Ekman et al., 2011). Health is no longer regarded purely as the presence of disease, but the patient's ability to adapt and self-manage. This radically alters how professionals, patients, and public engage with the subject of 'health' (Huber et al., 2011).

1.1 Objectives

- Identify the issues and barriers to a successful transition from paediatric to adult health care.
- Discover unmet needs not previously addressed in literature.
- Identify the most suitable design approaches for the future development of a design-based intervention.

2 METHODS

2.1 Aim of study

To explore healthcare professionals' and AYA's to gain their perspectives regarding the issues and barriers the face in the process transitioning from paediatric to adult care. From the themes emerging, we aim to bring to the early-stage potential area for a design-based intervention through a UCD and EBCD approach.

2.2 Research design

The research was conducted in 2 phases through a qualitive research approach, the first phase was a comprehensive literature review which presents a comprehensive overview of the transition process and the reported issues. Following from this, a search commenced in Design for Health and what would be the most appropriate design methodologies to mitigate issues that are arise in the second phase of study. In phase 2 of the study which involved interviews with HCPs' (n=8) and a focus group with AYA's (n=9) (July 2020- Feburary 2021).

2.3 Transfer of care

A seamless transition from paediatric to adult healthcare services is vital for adolescents wellbeing and long-term health (Stroud et al., 2015). Unfortunately, evidence indicates that a seamless transition is often hampered by insufficient preparation, poor service coordination, a lack in resources, and inadequate training and education. Many adolescents undergo an abrupt transfer from paediatric to adult health care services, thus they feel unprepared, have little knowledge of self-management skills and receive little information about the adult services (Burström et al., 2017, Dwyer-Matzky et al., 2018). Despite all the literature on the transfer and transition from paediatric to adult services, adolescents are not transitioning seamlessly into the adult system. Healthcare professionals find adolescent patients challenging as they are unaccustomed with their history, specific condition and unaware of their psychosocial needs (Coyne et al., 2019). Experts in the field agree on the fact that continuity of care is the key indicator for a successful transition (Suris and Akre, 2015).

2.4 Literature findings

Lack of integration among various silos and inadequate communication between providers causes delays in delivering appropriate health care services to these vulnerable patients and their caregivers, diminishing positive health outcomes and driving costs ever higher (Clarke et al., 2017).

Mortality and morbidity rise after an insufficient transition from paediatrics to adult services (Conti et al., 2018). Young patients are predominantly susceptible and can experience worsening of their disease.

Transition difficulties are undisputable for adolescents and can result in severe consequences when services fail them. Paediatric to adult healthcare transition can be especially difficult for these adolescents, as it occurs at a time in their lives when they are already experiencing many lifestyle changes that are influenced by education and personal development (Vaks et al., 2016).

Many protocols, procedures, models of care exist worldwide, however, universal implementation has not been realized and unmet needs continue to be reported (Clemente et al., 2017).

2.5 A grounded theory study

Through the application of a grounded theory research approach the researcher set out to discover or construct theory from data regarding the issues and barriers to a successful transition from paediatric to adult health care for AYA with JIA. It was premised problem that many AYA do not have successful transfer from paediatric to adult care and there is limited empirical evidence assessing the transition experiences (Coyne et al., 2019) . This use of a grounded theory approach allows for the researcher to remain open to all possible theoretical understanding.

2.6 Data collection

Semi structured open ended interviews were conducted with: 1 Adult Rheumatologist, 1 Adolescent Health expert, Dr.(P5), 1 Adolescent and Adult rheumatologist, 2 Advanced Nurse Practitioners, 1 in Paediatric Rheumatology, 2 in Adult Rheumatology, 2 Experts in the field of the transition of care 1 founder and chair of the Irish Children's Arthritis Network, 1 mentor for ICAN (adolescent expert in the field who has lived experience of the transition of care and now a mentor for adolescents and young adults going through the process). N=8, 5 female, 3 males, conducted July 2020 – Jan 2021.

Focus group with AYA's to investigate the issues and barriers from their perspectives. The focus group took a semi-structured form, with conversational prompts used to guide the conversation and promote input from all members. N=9, 6 female, 3 males, conducted in February 2021.

2.6.1 Data analysis

Data were subjected to inductive thematic analysis to distinguish prevalent themes correlating to the research objectives, the perspectives from the HCP's and experts in the field regarding issues and barriers to successful transition from paediatric healthcare services to adult healthcare services, and how these issues and barriers are experienced. Thus, informing further research to determine whether the lived experience create issues and barriers.

2.6.2 Coding of the data – Grounded theory coding

Open coding of the data to inductively allow conversation activities to emerge.

Grounded Theory Strategies Grounded Theory Strategies for Seeing for Seeing Data Anew

Engage in coding from the start of data collection-line-by-line, incident-by incident and/or situation by situation.

Compare data, data with codes, and codes with codes throughout inquiry: Integrates and streamlines data collection data collection and analysis.

Build inductive theoretical analyses inductive theoretical analyses (Charmaz and Thornberg, 2020)

2.6.3 Interview findings

Table 1. Themes from interviews with HCP's

Transition processes and preparation	Process of transition currently in paediatric and adult care Timing – available for HCP's v's right time for AYA's
Adaptive processes to the individual needs of AYA	Continuity of care Age-appropriate care
Relationships	AYA's with HCP's Caregiver with HCP's

2.6.4 Transition processes and preparation – Table 1

Transition practices - Process of transition currently in paediatric and adult care.
Most HCP's recognised that transition management process was informal with the lack of any specific guidelines, ad hoc transition management procedures were reported with no formal policies in place.

> *"there needs to be more written policies on it and documentation, instead of everyone just doing their own events, trying to do a bit of transition here and there…"*
>
> P3: Advanced Nurse Practitioner Paediatric Rheumatology

> " *You refer to the transition process, which there isn't really one, it's just, they refer to me … sort of usual thing this patient 16, can you see them? And I said yes, but I know that I won't see them for a year and a half".*
>
> P1: Adult Rheumatology Consultant

Transition clinics were deemed to be the best practices however there were barriers encountered in performing these to the best of the HCP's abilities due to various factors.

> "*that was probably the preparation that the work that we did with them, that if they felt prepared. When we had done it gradually over the year*"
>
> P3: Advanced Nurse Practitioner Paediatric Rheumatology

2.6.5 Adaptive processes to the individual needs of AYA's – Table 1

Due to the lack of formal processes and procedure the process is not meeting the needs of the AYA and the HCP's are aware of this:

> " *every child is so, so different, and this is, this is the thing… it's just it's just working with that individual child".*
>
> P2: Advanced Nurse Practitioner Adult Rheumatology

Through the data gathered HCP's with expertise in AYA's health the recommendations are for age appropriate care, however, does age appropriate care address the needs of the individuality of the AYA's.

> "*moved away from kind of a just a transition model which is very focused on getting someone out of the hospital and into a different hospital and they're moved towards age-appropriate care, which is adolescent clinics and young adult clinics, kind of trying to tailor needs to the individual* ".
>
> P7: Adolescent and Adult Rheumatologist

AYA's strive to be the same as their peers and is the process of adding further complexity to their developing adding unnecessary complexities to an already complex period in their development.

> *" like it's so important to be the same and to fit in… to look different, you know to be shorter or skinnier… have to miss school you know for appointments, have to inject yourself has to have, you know, different physical appearance or whatever. I cannot imagine how hard that is like it is hard enough to be a teenager baseline…, if given a choice between fitting in with their friends and taking their medications on time, for sure it's only natural that they're going to want to fit in their friends like that's like that's normal".*
>
> P6: Adolescent Health Expert

2.6.6 Relationships – shifts in responsibilities – Table 1

AYA’s with HCP’s Paediatric care

There is a misapprehension of the needs of the AYA’s from the perspective of the HCP’s, by not understanding these needs during this turbulent period of the young adults’ lives may create issues with adherence as they may feel misunderstood.

> *” there’s kind of a misconception out there that teenagers are healthy, that they're grand, you know what I mean and also they're just not coming to clinic… they are only going through a phase and they will come back around and there's no point in chasing them, you know what I mean”.*

P8: Adolescent Health Expert

The role of the HCP’s can be seen to be a determining factor in the relationship between the HCP and the young adult. There is a sense that the HCP job is to just treat the medical problem.

> *“I don't know and maybe I'm not that interested. I am there to do a job. And if I do that, if they want, they can, they can engage in us if they do not want to there is nothing, I can do”.*

P1: Adult Rheumatology Consultant

2.6.7 Focus group findings.

Table 2. Themes from FG with AYA’s

Communication	Talked too not with Misunderstood
Individuality	Lack of awareness to individual needs
Understanding and empathy	AYA’s with HCP’s Paediatric care v’s adult care

2.6.8 Communication - Table 2

AYA’s feel their needs are not being addressed in paediatric care.

> *“And you do a lot more talking, than in hospital X they kind of baby you, that kind of way. They will do everything. Where in adult service, you must ask for everything, but I was so much happier in adult service than I was in children's services. And because they can, they are actually listening to you”.*

Not consulted about their lived experiences

> *“You have to experience it for yourself before you can judge anything about it. So, like I'd say if you did a full day in Child Services, and in if you were able to sit in a consultation, with a patient you will see how they actually do it. And after you after they do that, you go speak to the family and ask how did you feel about that? And then you will actually see what it's like to be a child in X with JIA”.*

There is no communication between the different services, possible negative impacts as a result of this, adherence to healthcare regime.

> *Communication between doctors, so between child and adult services, from adult services to child services. And then back to you. The communication is not there. There is no communication.*

P4. Early post transition phase

In child services speak at not with, there is no sense of common ground. Whereas in the adult services they feel more involved in the process.

> *“I think it’s an understanding, I think it's more than they actually explain it to you… In child services they say different words and you're like what are these words? Where in adult services they actually explain those words. Ask them what is, and they'll explain it. Like it is all about the communication between your doctor”.*

P7. Early post transition phase

2.6.9 Individuality - Table 2

The impact of the feeling of rejection

> *“They probably, they probably wouldn't be able to sorry, you're not part of hospital X anymore, you're moved on, cut off service. So that's why you kind of have to, you kind of have to be very independent when moving. And you just have to take it on the chin”.*

P7. Early post transition phase

Lack of awareness of the wants and needs of the cohort, as highlighted in the levels of communication in the child services.

> *"X needs to, like think of like when they say, I think when we turn a certain age in teens, 14, 15, 16, they have to realize that we're not like 8, 9,10, 12. Like we have to be treated a bit different. Like when you go into X. And you're in the waiting room and there's like six-year-olds in there waiting as well…".*

P5. Early post transition phase

2.6.10 Understanding - Table 2

Lack of empathy

> *"She asked Hospital X to do a referral and they she was told that you are not part of X but we will send it and hope for the best. Like even they are saying, you know you're not part of X anymore. Like that's kind of like stab in the back".*

P2. Early post transition phase

This also relates to the levels of communication between the various healthcare professional and their understanding of the needs of the AYA's.

> *"I feel like they just have they have one checklist. And they are going to stick to that no matter what. Yeah, like they don't want to hear anything different".*

3 DESIGN FOR HEALTH

The healthcare sector is a complex system that is facing new emerging trends without, however, having the proper resources and structures to address them. The necessity for a change in the approach to new challenges of the healthcare sector provides a stimulating field of application for design disciplines.

The fundamentals of design thinking are a systematic innovative process that highlight the importance of the end-users needs, desires, and challenges they face. One must begin with research and empathy with the people affected by and knowledgeable about the product, service, system, or experience that needs changing (Chapman, 2016). Developing solutions to the numerous multidimensional challenges facing the health of individuals and communities remains an arduous challenge in healthcare. Core methods in design thinking can differ between various authors and practitioners, the methods that are most widely accepted and that apply to healthcare administration are developing empathy, radical collaboration, and an iterative approach (Roberts et al., 2016).

Design and human behaviour are intrinsically linked (Deterding, 2015). The design of objects and how services are configured all evoke ways of responding and behaving. Curiosity in this relationship between design and behaviour change has been evolving mainly in the context of the broader healthcare environments. This interest stems from a rising recognition that when certain behaviours have been adopted there has been an enhancement in health outcomes and quality of life (Alcorn & Broome, 2014). Designing appropriate products and services for the outlined stakeholders requires deep unprejudiced understanding of their needs. One consensus across literature concerning methods in designing for adolescents is maintaining 'user centricity'. The user-centric design ethos suggests keeping users and key stakeholders central to research and included in methodologies (Norman, 2013). This contrasts with designers having the sole responsibility of assuming what people require. UCD keeps focusing on the user throughout the design process with the view that this potentially links to better design output. There is growing evidence that designing health systems with the patient at the centre is an appropriate way to address the needs of people with chronic conditions (Harkness, 2005).

3.1 User-centered design in healthcare

Many studies have been performed to utilize UCD in the healthcare setting, however many they have not exploited the use of UCD to its full capabilities. From the study performed by Birnbaum (2015) regarding the necessity of patient engagement for the design of digital health. Digital health is an area of growing interest for physicians, patients, and technology companies equally. It assures the ability to engage patients in their care, before, during, and after an emergency department visit. Current efforts to create, study and circulate digital health have been limited by a lack of user engagement (Birnbaum, 2015). Within this study, there was a lack of empathy for the patient needs as their opinions were not fully assessed in identifying these requirements. During this study, the user was only included at various phases thus their needs were not accurately represented.

In the study conducted by Katsulis (2016) titled ‘Iterative user centered design for development of a patient-centered fall prevention toolkit’. The UCD process was implemented, however, limitations did occur where the prototypes developed as solutions to the highlighted problems were final versions. This did not allow for the iterative nature of the UCD process to be fully explored and did not account for adequate feedback in the development of a possible solution (Katsulis et al., 2016). Therefore, the UCD process was not entirely executed. Providing patient-centered care necessitates that patients partner in their personal health-care decisions to the full magnitude desired. Design research has long since examined human behaviour and its role in design. A distinction can be made between the behaviour of designers and that of users, customers or other stakeholders. Studying the behaviour of designers helps us to understand and improve the design activities or processes that they engage in (Lindemann, 2003). Studying the behaviour of users, customers or other stakeholders is an established approach towards gathering information about unmet needs or how people interact with designed artefacts. Understanding the behaviour of customers/users also plays a pivotal role in behavioural design, which describes the design of products or interventions that incorporate behaviour change strategies (Cash et al., 2017).

3.2 Design healthcare models

Increased attention has been given to the potential design theory and practice for improving health services (Hurley et al., 2016). Within the scope of UCD, experience-based co-design (EBCD) can be found, this is said to be a participatory research approach that amalgamates design tools and design thinking by bringing healthcare staff and patients perspectives together to enhance their quality of care (Gustavsson and Andersson, 2019). EBCD is a method utilised for improves in healthcare services, it combines participatory and user experience design tools and process to bring about quality enhancements. Through a ‘co-design’ process the approach involves staff, patients and carers allowing them to reflect on their lived experiences of the service. Through a multidisciplinary approach they identify improvement priorities, designing and implementing changes, then reflecting on their achievements (Fucile et al., 2017). Fucile (2017) conducted a study using EBCD to improve the patient and their families’ experiences in the Oncology Clinic in Ontario Canada, the outcomes of that study identified key ‘touchpoints’ to improve the cancer patient and their families’ interactions with the Oncology clinic. The results of the study gave the healthcare professional a true insight to the needs of the users of the systems. The study proved to be very successful to improve the patients’, and their families’ experiences of the system.

3.3 Universal design and healthcare

Universal design arose in response to accessibility laws the Fair Housing Act Amendments, 1988; and the Americans with Disabilities Act of 1990), which specified minimum accessibility requirements for products and built environments. Product designers and architects working to meet these requirements developed a universal design to create and modify products and built environments to allow the fullest use possible among the greatest number of people (Meyer et al., 2014). Benefitting people with and without disabilities, the concept of universal design was expanded into education to create curricula and classroom environments that would reach the most children with the least amount of modification: an approach called universal design for learning (UDL) (Bassuk et al., 2017). The recent outcry for more responsive and compassionate health care, sets up an imperative for developing a universal design to address the needs of people with a wide range of health needs. Providers and service users become partners in relationships that encompass the “qualities of compassion, empathy, and responsiveness to the needs, values, and expressed preferences of the individual patient.” These qualities are at the heart of PCC, “which is based on deep respect for patients as unique living beings, and the obligation to care for them on their own terms.” Despite growing attention to PCC based on a “whole- person orientation” that integrates medical home principles, (Control and Prevention, 2011) this approach has not been widely implemented in hospital systems (Care et al., 2016).

4 RESULTS AND DISSCUSSION

There are several emerging themes from the interviews conducted with the HCP's and AYA's regarding issues and barriers to a successful transition from paediatric to adult health care, however the most predominant themes will be extracted to be further explored and how the use of various design methodologies can be utilized to mitigate these issues. Many product systems and services within healthcare settings have been designed by experts for experts this can lead to these systems creating a daunting experience for the patient within healthcare settings (Reay et al., 2017). The most predominant theme arising from the interviews was that of an understanding that all AYA's are individual and have very individual needs, from the perspective of one HCP they stated the need for age-appropriate care however it remains to be seen if this care delivery method fulfils the needs of the AYA's. From the study conducted by Sawyer (2019) for developmental appropriate care for adolescents the study reported positive findings to this approach in the delivery of care, however many AYA's who took part in the study reported they had unmet needs this may have been due to the fact that they may not have been forthcoming with their actual needs and methods used for the study did not unearth these needs (Sawyer et al., 2019). Through a well-executed UCD, EBCD and Universal Design approach, the opportunity exists to develop a product or system service to ease the transition from paediatrics to adult health care. UCD, EBCD and Universal design have been deemed to be the best approach to devise the most appropriate and user-friendly solutions for all stakeholders intertwined in the transition process. However, there are some challenges associated with the usage of the UCD approach for improving the transition from paediatrics to adult healthcare as all needs from all the stakeholders in the process must be carefully assessed to ensure the best and most appropriate solution is identified. This will mitigate against the possibility of a suboptimal solution being chosen. The iterative and holistic nature of the UCD allows for the development of the most appropriate solutions. All stakeholders will actively be involved throughout the research and design process to ensure their needs are being addressed. Persistent feedback and input from all stakeholder groups will true needs and wants are being addressed. Actively having the stakeholder groups involved throughout the process will engage the end users' opinions to feel valued. A significant part of the UCD process is an account for real-world situations and context of use, or system processes. The UCD process engages the stakeholders often and early in the research and development of possible solutions. It permits all stakeholders to have an active input during all stages of the process allowing them more input in forward solutions.

5 LIMITATIONS AND FUTURE WORK

We purposefully chose a diverse range in skillset in HCP's and experts in the field for the interviews, we aimed to get the perspectives of Paediatric Rheumatology Consultants and Advanced Nurse Practitioners actively involved in the transition process. However, due to shifts in responsibilities of these HCP's in line with excessive demand on the Healthcare system currently some of their perspectives have not been attainable to date. The findings from the AYA cohort are preliminary and need to be built upon further. Challenges have also arisen in engaging AYA in the research as many who have been through the process are not at in at stage in their lives where they just do not want to acknowledge their experience. Next steps are the design of an interactive research approach to engage the AYA's to gain their experiences of the system and how they felt about the process while also unveiling their unmet needs.

6 CONCLUSION

Traditionally health research has mainly been performed through quantitative methods, and due to the nature of quantitative data gathering, it is not very user-centric and does not allow for empathy of the system-users' wants and needs. therefore, a user-centered design approach is regarded to be the most desirable method to be utilized to develop user-centric outcomes. Involving patients directly during the design process for creating more patient centric solutions may be a substantial development of their adherence to the process as they transition from paediatric to adult care and thus there may be less successful transitions reported. The user-centered approach allows us to look at the system from a more holistic viewpoint. As previously stated, healthcare is addressed in various silos and the UCD and EBCD processes will enable this issue to be possibly mitigated in the future.

The novel approach to this study is the engagement of the AYA's in every stage of the process, making them feel active participants as they will co-design an intervention that will aid in the future generations not feeling their voice is not heard or valued.

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